NOTE

This Microfiche meets the quality requirements of the American National Standard for Microfiche of Documents (ANSI PH5.9-1975). However, because of imperfections in the document from which it was made, it contains images that are illegible or difficult to read. The source document for this microfiche is the best copy that could be obtained prior to filming.

CIS

Congressional Information Service, Inc.
Washington, D.C.

DOUBLE DUTY: CARING FOR CHILDREN AND THE ELDERLY

HEARING

BEFORE THE

SELECT COMMITTEE ON CHILDREN, YOUTH, AND FAMILIES HOUSE OF REPRESENTATIVES

ONE HUNDREDTH CONGRESS

SECOND SESSION

HEARING HELD IN WASHINGTON, DC, MAY 3, 1988

Printed for the use of the Select Committee on Children, Youth, and Families

U.S. GOVERNMENT PRINTING OFFICE
86-514 WASHINGTON : 1988

For sale by the Superintendent of Documents, U.S. Government Printing Office
Washington, DC 20402

H961-56.

SELECT COMMITTEE ON CHILDREN, YOUTH, AND FAMILIES

GEORGE MILLER, California, *Chairman*

WILLIAM LEHMAN, Florida
PATRICIA SCHROEDER, Colorado
LINDY (MRS. HALE) BOGGS, Louisiana
MATTHEW F. McHUGH, New York
TED WEISS, New York
BERYL ANTHONY, Jr., Arkansas
BARBARA BOXER, California
SANDER M. LEVIN, Michigan
BRUCE A. MORRISON, Connecticut
J. ROY ROWLAND, Georgia
GERRY SIKORSKI, Minnesota
ALAN WHEAT, Missouri
MATTHEW G. MARTINEZ, California
LANE EVANS, Illinois
RICHARD J. DURBIN, Illinois
THOMAS C. SAWYER, Ohio
DAVID E. SKAGGS, Colorado

DAN COATS, Indiana
THOMAS J. BLILEY, Jr., Virginia
FRANK R. WOLF, Virginia
NANCY L. JOHNSON, Connecticut
BARBARA F. VUCANOVICH, Nevada
JACK F. KEMP, New York
GEORGE C. WORTLEY, New York
RON PACKARD, California
BEAU BOULTER, Texas
J. DENNIS HASTERT, Illinois
CLYDE C. HOLLOWAY, Louisiana
FRED GRANDY, Iowa

Committee Staff

Ann Rosewater, *Staff Director*
Mark Souder, *Minority Staff Director*
Carol M. Statuto, *Minority Deputy Staff Director*

CONTENTS

Page

Hearing held in Washington, DC, on May 3, 1988 1

Statement of:

- Brady, Patricia, Mahopac, NY 8
- Brody, Elaine M., Associate Director of Research, Philadelphia Geriatric Center, Philadelphia, PA 78
- Frances, Dorothy, Friendly Visitor, Retiree Service Department, International Ladies' Garment Workers Union, New York, NY 91
- Johnson, Kenneth G., M.D., Director, National Interfaith Volunteer Caregivers Program, and Adjunct Professor of Community Medicine, Mount Sinai School of Medicine, New York, NY 67
- Kornblatt, Susan, Member, Board of Directors, Family Survival Project, and Gerontologist, University of California, San Francisco, CA 49
- Lane, Nancy, Soddy Daisy, TN 23
- McEuen, James E., Bethesda, MD 30
- Nestor, Al, Director, Franconia Family Therapy Center, Alexandria, VA... 98
- Singleton, J. Knox, Chairman, Volunteer Development Committee, Fairfax County Commission on Aging, Fairfax, VA 87
- Warnock, Arleen, Brooklyn, NY 18
- Warnock, Deborah, Brooklyn, NY 15

Prepared statements, letters, supplemental materials, etc.:

- Brady, Patricia, Mahopac, NY, prepared statement of 11
- Brody, Elaine M., Philadelphia Geriatric Center, Philadelphia, PA, prepared statement of 82
- Emlen, Arthur C., Paul E. Koren, and Dianne Louise, Child and Elder Care: Final Report of an Employee Survey at the Sisters of Providence, Portland, OR: Regional Research Institute for Human Services, Portland State University, 1988, Excerpt From 118
- Frances, Dorothy, retiree of the International Ladies' Garment Workers Union, New York City, prepared statement of 94
- Johnson, Kenneth G., M.D., director, National Interfaith Volunteer Caregivers Program, Adjunct Professor of Community Medicine, The Mount Sinai School of Medicine, New York, NY, prepared statement of 70
- Kane, Barbara, licensed clinical social worker and co-director of Aging Network Services, Inc., Bethesda, MD, prepared statement of 121
- Kornblatt, Susan, member of the Board of Directors of the Family Survival Project (FSP), San Francisco, CA:
  - Annual report of the Statewide Resources Consultant, Programs for Brain-Impaired Adults and Their Families, 1987, from Family Survival Project 62
  - "Overworked, Underestimated: the Employed Caregiver Doing Double Duty," A Research Summary from Family Survival Project, article entitled 58
  - Prepared statement of 53
- Lane, Nancy, Soddy Daisy, TN, prepared statement of 26
- McEuen, James E., Bethesda, MD, prepared statement of 35
- Miller, Hon. George, a Representative in Congress from the State of California, and Chairman, Select Committee on Children, Youth, and Families:
  - "Double Duty: Caring for Children and the Elderly" (a fact sheet) 4
  - Opening statement of 2
- Nestor, Al, LCSW, director, Franconia Family Therapy Center, Alexandria, VA 101

Page

Prepared statements, letters, supplemental materials, etc.—Continued
- Roberts, A. Jane, Ph.D., Member AARP State Legislative Committee for Iowa, Des Moines, IA, prepared statement of 127
- Singleton, Julius Knox, Burke, VA, prepared statement of 89
- Warnock, Arleen, Brooklyn, NY, prepared statement of 20
- Warnock, Deborah, Brooklyn, NY, prepared statement of 16
- Wortley, Hon. George C., a Representative in Congress from the State of New York 45

DOUBLE DUTY: CARING FOR CHILDREN AND THE ELDERLY

TUESDAY, MAY 3, 1988

House of Representatives,
Select Committee on Children, Youth, and Families,
Washington, DC.

The committee met pursuant to call at 9:15 a.m., in room 2226 Rayburn House Office Building, Hon. George Miller (chairman of the committee) presiding.

Members present: Representatives Boggs, Weiss, Martinez, Evans, Durbin, Coats, Wolf, Johnson, Wortley, Packard, Hastert, Holloway, and Grandy.

Also present: Representatives Fish and Morella.

Staff present: Ann Rosewater, staff director; Jill Kagan, professional staff; and Ann Turnbull, congressional fellow.

Chairman Miller. The Select Committee will come to order.

Today, the Select Committee on Children, Youth, and Families will explore a new and emerging issue: the concerns of members of the baby boom generation who find themselves caring for both their elderly parents and their own children at the same time.

This new generation of caregivers is different from any other in American history. Healthier life styles and lifesaving medical technologies have lengthened the life span of aging adults as well as children with severe disabilities and chronic illnesses. At the same time, fewer family members are available to provide care. The growing participation of women in the work force, greater separation of extended families, and the increasing number of single-parent families have affected the ability of families to take care of their own.

As a result, family members are often compelled to juggle careers, nursing duties, housework, and the nurturing of two sets of dependents. This "double duty" takes its toll. Family caregivers who work full-time frequently spend more hours every day providing care than they do at their job. Emotionally and physically, they pay the price in depression, anxiety, fatigue, illness, isolation, fear of the future, and guilt over not doing more.

The financial toll can also be particularly steep. A significant proportion of family members are forced to quit their jobs to fulfill their duties at home. New data from the National Center for Health Services Research suggest that single parents, primarily women, who shoulder responsibility for both children and elderly parents are the most vulnerable. They were less likely to be working than those without family responsibilities.

Despite the serious strains on family caregivers, supports such as respite care, attendant, homemaker or nursing services which help families manage care are expensive and difficult to arrange. In many communities, such services are simply unavailable.

We will learn today, however, that when support services such as respite are available, even families coping with an Alzheimer's sufferer are able to continue providing home care for an extended period of time. Although most families who had the benefit of the respite program viewed it as a last resort, often waiting until they were on the verge of a breakdown to use it, they desired more respite care in the coming year than any other service.

As we will hear today, families remain committed to caring for their elderly parents or children in home and community settings. But never before have families been asked to handle so many responsibilities simultaneously. Families are doing their part and more. The question we must ask today is how public and private resources can contribute to easing these new responsibilities.

This morning we will hear from families who are providing care both to children, including disabled or chronically ill children, and to dependent elderly parents. And our witnesses will include researchers as well as providers of support and respite for families. I welcome all of you to the hearing.

The first panel that the committee will hear from will be made up of Patricia Brady from Mahopac, New York, Deborah and Arleen Warnock from Brooklyn, New York, Nancy Lane from Soddy Daisy, Tennessee and James McEuen from Bethesda, Maryland. Come forward, please. Welcome to the committee. All relax and settle down here. It is a very relaxed committee.

OPENING STATEMENT OF HON. GEORGE MILLER, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA, AND CHAIRMAN, SELECT COMMITTEE ON CHILDREN, YOUTH, AND FAMILIES

Today the Select Committee on Children, Youth, and Families will explore a new and emerging issue: the concerns of members of the baby boom generation who find themselves caring for both their elderly parents and their own children at the same time.

This new generation of caregivers is different from any other in American history. Healthier lifestyles and lifesaving medical technologies have lengthened the lifespan of aging adults as well as children with severe disabilities and chronic illnesses. At the same time, fewer family members are available to provide care. The growing participation of women in the workforce, greater separation of extended families, and the increasing numbers of single-parent families have affected the ability of families to take care of their own.

As a result, family members are often compelled to juggle careers, nursing duties, housework, and the nurturing of two sets of dependents. This "double duty" takes its toll. Family caregivers who work fulltime frequently spend more hours every day providing care than they do at their job. Emotionally and physically, they pay the price in depression, anxiety, fatigue, illness, isolation, fear of the future, and guilt over not doing more.

The financial toll can also be particularly steep. A significant proportion of family members are forced to quit their jobs to fulfill their duties at home. New data from the National Center for Health Services Research suggest that single parents—primarily women—who shoulder responsibility for both children and elderly parents are the most vulnerable. They were less likely to be working than those without family responsibilities.

Despite the serious strains on family caregivers, supports such as respite care, attendant, homemaker or nursing services which help families manage care are expensive and difficult to arrange. In many communities, such services are simply unavailable.

We will learn today, however, that when support services such as respite are available, even families coping with an Alzheimer's sufferer are able to continue providing home care for an extended period of time. Although most families who had the benefit of the respite program viewed it as a last resort, often waiting until they were on the verge of a breakdown to use it, they desired more respite care in the coming year than any other service.

As we will hear today, families remain committed to caring for their elderly parents or children in home and community settings. But never before have families been asked to handle so many responsibilities simultaneously. Families are doing their part and more. The question we must ask today is how public and private resources can contribute to easing these new responsibilities.

This morning we will hear from families who are providing care both to children, including disabled or chronically ill children, and to dependent elderly parents. And our witnesses will include researchers as well as providers of support and respite for families. I welcome all of you to the hearing.

FACT SHEET
"Double Duty: Caring for Children and the Elderly"

CHILDREN, ELDERLY FAMILY MEMBERS NEED CARE

* In 1985, an estimated 26.5 million children under age 15 had mothers in the labor force; 16.8 million had mothers who worked full time. If current female labor force participation trends continue, by 1995 over 3/4 of school-age children (34.4 million) and 2/3 of preschool children (14.6 million) will have a mother in the workforce. (U.S. Bureau of the Census [Census], 1987; Hofferth and Phillips, 1987)

* Twenty million children have a chronic physical or mental condition; 3.2 million are limited in their daily activities because of their disability. Children in poverty are almost 50% more likely to have a disability than children from higher income families. (Fox, 1987)

* Among the elderly, the need for care increases with age: 13% of the 65-74 age group, 25% of the 75-84 age group, and 46% of the 85 and over age group need care. (National Council on the Aging, 1987)

* In 1982, there were 1.2 million frail elderly receiving informal care. Of the elderly citizens receiving care from their families, the majority are female, 1/3 have family incomes in the poor or near-poor range, and slightly over 2/3 are in fair or poor health. (Stone, Cafferata, & Sangl, 1987)

MOTHERS SERVE AS PRIMARY FAMILY CAREGIVERS; MANY ALSO WORK

* In 1982, almost 2.2 million individuals 14 or older provided unpaid assistance to 1.2 million noninstitutionalized elderly persons with a disability. More than 70% of the caregivers were female, and of these, almost 30% were daughters. Twenty-five percent of adult children caring forelderly parents had simultaneous responsibility for children. The average age of female caregivers of elderly parents is 57.3 years and 31% are employed. (Stone, Cafferata, & Sangl, 1987)

* Twenty-eight percent of the home-office employees at a Hartford-based insurance company provide care for an elderly relative or friend. Among employees ages 30-40 in this group, 29% have children under age 6; 43% have children 6-18. Of those ages 41-55 in this group, 4% have children under age 6; 37% have children 6-18. (The Traveler's, 1985)

* In 1987, 57% of mothers with children under 6, and 71% of mothers with children ages 6-17 were in the labor force. Nearly 3/4 (74%) of all employed mothers with school-age children ages 6-17, and 2/3 (67%) with children under six worked full-time. (Bureau of Labor Statistics [BLS], 1987)

- Thirty-eight percent of the primary caretakers of children with chronic health conditions are employed. (Human Services Research Institute, 1985)

- Forty-nine percent of married working mothers report full responsibility for home chores compared with 4% of married working fathers. (Burden and Googins, 1985)

- When a child is sick, female employees are 6 times as likely to stay home and provide care than are male employees. (Burden & Googins, 1985)

VULNERABLE FAMILIES LOSE INCOME TO PROVIDE CARE

- In 1982, while the majority of family caregivers of the elderly reported adjusted family incomes in the low to middle range, almost 32% had incomes falling within the poor or near-poor category. Nine percent of all caregivers (12% of caregiving daughters) reported they left the labor force to care for a disabled relative or friend. (Stone, Cafferata, and Sangl, 1987)

- Among one sample of women caring for elderly parents in the Philadelphia area, 13% found it necessary to quit their jobs; 40% of them had family incomes of less than $15,000 a year. (Brody, 1988)

- In California, a survey of Bay Area caregivers revealed that 22% of those who were not employed outside the home had quit their jobs to give care. Their estimated lost annual income was $20,400 each. (Family Survival Project, 1988)

- Thirty-six percent of mothers in families with incomes less than $15,000/year said they would look for work if child care were available at a reasonable cost. (Census, 1983)

FAMILY CAREGIVING: MORE THAN A FULL-TIME JOB

- Both male and female employees who are parents spend from 15 to 25 more hours per week on combined family and work responsibilities than do employees who are not parents. (Burden & Googins, 1985)

- Families provide 80%-90% of the medical and personal care, household tasks, transportation, and shopping assistance of elderly members requiring care. (Brody, 1985)

- Approximately 80% of the caregivers of elderly persons provide assistance 7 days per week for an average of about 4 hours per day. (Stone, Cafferata, & Sangl, 1987)

- On the average, caregivers employed outside the home spend 47 hours each week providing care to an elderly or adult family member who lives with the caregiver, exceeding the time they spend at the job. Family caregivers who do not work outside the home spend an average of 18 hours per day giving care. (Family Survival Project, 1988)

- Daughters provide the same amount of assistance to elderly parents regardless of the number of children they have or the ages of their children. (Stoller, 1983)

CAREGIVING TAKES TOLL AT HOME AND IN THE WORKPLACE

- * Seventy percent of women with double care responsibilities report stress and worry about family finances compared to 64% of mothers with child care needs only and 59% providing adult care only. (Emblen, 1988)

- * A significant problem of families who provide care is fear about the care recipient's condition and uncertainty about the nature of illness and treatment. (Masciocchi, 1985)

- * The most negative consequences of caregiving are emotional strain including depression, anxiety, frustration, and helplessness. (Brody, 1985)

- * More than 450,000 parents have their jobs disrupted each month by difficulties with child care arrangements. (Census, 1987)

- * In a survey of 400 men and women with children under 12, 41% lost 1 day of work in the prior 3 months to care for family matters. Child care problems were found to be the most significant predictors of absenteeism and limited productivity. (Galinsky, 1987)

- * Approximately 3/4 of female caregivers of elderly family members report a conflict between work and caregiving and 35% report that caregiving has affected work. (Gibeau, 1987)

- * On the average, women miss 1 week of work per year due to caregiving of an elderly family member. One survey indicated that women in the highest occupational group (professional and managerial) missed the most work hours and were most likely to identify work and caregiving conflicts. (Gibeau, 1987)

CHILD CARE AND FAMILY SUPPORT NEEDED, BUT HARD TO COME BY

- * In a survey of families providing care for adult or elderly members, 52% needed information, 38% needed respite services, and 35% needed emotional support. (Family Survival Project, 1987)

- * In 1980, respite care was the need most frequently identified by state social services for families with developmentally disabled children. In a survey of caregivers of Alzheimer's sufferers, respite care was desired more frequently than any other service. (Cohen and Warren, 1985; Brody, 1988)

- * Seventy-three percent of women caring for children and elderly persons report difficulty finding adult care compared to 66% looking for adult care only, and 55% report difficulty paying for child care compared to 48% of mothers with only child care needs. (Emblen, 1988)

- * A 20-site workforce survey revealed that only 5% of women caring for both children and elderly persons claimed a tax credit for adult dependent care. (Emblen, 1988)

- * While low-income, female-headed households account for 80-90% of the families receiving child care subsidies through some combination of federal, state, and local funds, many states are serving less than 30% of their eligible population. (Marx, 1987)

- In FY 1987, the largest federal spending program that provides child care assistance and social supports for the elderly (the Title XX Social Services Block Grant) was worth only half its FY 1977 level, when adjusted for inflation. (Children's Defense Fund, 1987)

Chairman MILLER. Welcome to my distinguished colleague, Mr. Fish. How are you?

Did you come to introduce one of the witnesses?

Mr. FISH. Yes.

Chairman MILLER. I want to say to all of the witnesses we will include your written statement in the written record of the hearing. When it is your turn to testify, just proceed in the manner in which you are most comfortable. We will hear from all of you and then we will come back and ask you questions.

Hamilton, we will start with you.

Mr. FISH. Thank you, Mr. Chairman. I appreciate this courtesy and am most pleased to introduce to you my constituent, Mrs. Patricia Brady of Mahopac, as it ~~is~~ pronounced, which is in Putnam County in New York. I think that when you hear her testimony, you will feel, as I do, that Mrs. Brady is quite an extraordinary woman who bears a tremendous triple responsibility of interest to this committee, in caring for elderly parents, the grandmother, as well as a profoundly disabled child.

She is here today to tell you the story, a very gripping story, as well as to advise you about a parent advocacy group which has helped her ease her burden. That group is SKIP. It is a great privilege for me to welcome Mrs. Brady to the panel.

Chairman MILLER. Welcome to the committee. We will start with your testimony.

STATEMENT OF PATRICIA BRADY, MAHOPAC, NY

Ms. BRADY. My name is Patricia Brady. Some call me special. I am really quite an ordinary women living with extraordinary circumstances. I have come here today to tell you of my unique family and our survival. My grandparents left Italy and Ireland and came to this country in search of their dreams, where they met, married, and raised their families in Greenwich Village. My parents met, married, and stayed in our version of Hometown USA where they raised myself and my two brothers.

In 1979 I married Laurence Brady, a Vietnam War Veteran and Bronx boy. We and my parents decided that a home which would accommodate them in retirement, my paternal grandmother who was 84 and living alone, and our future children who would be watched by grandparents while we continued to work, as an excellent plan for tomorrow and we were looking forward to becoming the American family of the eighties.

In 1980, we purchased a home in Mahopac, New York a hamlet 60 miles from mid-town Manhattan. My husband and I commuted to work daily, to the Big Apple and dad retired from his job of 30 years with the Post Office. We were very happy. Previously purchased property was going to be sold and the monies used to convert the downstairs into an apartment for my parents and grandmother. I was slinging pasta, boiling potatoes, holding down a managerial position, thriving as a newlywed, proud of my appearance and quite content with what I had created.

In 1985, our first son, Mathew, was born by emergency C-section at our local hospital. Mathew was born dead, revived, and transferred by special ambulance to Neo-Natal ICU at New York Hospital. For anyone who needs a glimpse into the future, this unit looks like a set from Star Trek. Mathew spent the first seven months of his life in the hospital and we were handed a very grim outlook for the future.

My son's care is constant and must be consistent 24 hours a day. He has a tracheotomy which requires suction and high mist humidity, and medication to open his lungs. He had a tube surgically placed into his stomach to nourish him with a liquid diet which is dripped in by an electric pump. He has unrelenting, painful ear infections. He seizes sometimes constantly and cannot speak.

Do any of you question my sobriety in describing my son's extremely demanding life circumstances? Perhaps my calm affect is due in part to the fact that I have learned that I am not alone, for there has been someone who has heard my son's silence—Margaret Mikol from SKIP of New York.

Parent advocacy groups such as SKIP of New York have helped me come to terms with the most wonderful person it has been my honor to know. Let me introduce you to my son. This defiant individual is short on patience, unwilling to remove his hand from his buzzer until you respond to what he is mandating. The reward for this proper and timely response is a smile that lights up my world.

Three years ago, unbeknownst to me, Mathew's fragility, coupled with society's difficulty in coping with Mathew and his rapidly growing number of friends has thrust me into a new managerial position heretofore unrecognized and uncompensated. The intricacies of my 24-hour a day, seven-day-a-week job can only be compared to getting the annual budget passed.

I have become my son's full-time case manager, social worker, primary caregiver, systems liaison, and program designer; in addition to, remaining his mother, Larry's, wife, Lou and Elizabeth's daughter and Angelina's granddaughter. Corporate headquarters for these activities is my kitchen counter between the hours of 9:00 a.m. to 9:00 a.m. I am running IBM from my kitchen. When 3:00 a.m. rolls around, I dream of the luxury of having a paper shredder.

When grandma is having another of her multiple heart attacks and my son's cardiac monitor begins beeping, I know what my responsibilities are. And what is really poignant about this job is that I cannot fail. Grandma has gotten her 92-year-old priorities all straight. She categorically refuses to deal with the inconvenient myriads of paper generated by Blue Cross/Blue Shield, Medicare, and Medicaid, designating me her business manager. It has been reported that grandma would much prefer to entertain the young, good-looking interns, than to dwell on her disabilities.

The dream of an extended family unit, taking care of themselves, for us, is dying. My 68-year-old father is cleaning cars in a car rental business to put food on the family table, as our income is insufficient. My 65-year-old mother suffers with emphysema and bouts of severe depression.

My husband's blood pressure skyrockets. I am no longer gainfully employed. I no longer hold a position or title. I no longer have credit. My pension funds and savings are gone. The property to be sold to finance the downstairs apartment was sold at a quick sale and the funds used to live on and pay debts. We remain living all together in one unit.

In fairness to myself, my husband and Mathew and the unborn, I plan no more children. Our dream home and property are falling apart. We have gone from Yuppies to major financial burdens. I have become trapped by my own plan. My competence and willingness to do it all has allowed a system to expect my working mandatory overtime.

I am not alone. Many women in varying socio-economic strata are in my position. I cannot fail; for if I do, my grandmother and son will be institutionalized and my folks will not be helped in their late years. The choice is to forfeit my son and family for myself. This is not a choice. It is an act of defeat. I am calling upon this representation to remember me and the growing numbers of families like mine when considering legislation that affects my family, my child, my kind. We are women, capable, willing, hungry to contribute to the well-being of our society if given the opportunity to be a part of it.

PREPARED STATEMENT OF PATRICIA BRADY, MAHOPAC, NY

My name is Patricia Brady. Some call me special. I'm really quite an ordinary woman living with extrodinary circumstances. I have come here today to tell you of my unique family and our survival. My grandparents left Italy and Ireland and came to this country in search of their dreams, where they met, married and raised their families in Greenwich Village. My parents met, married and stayed in our version of Hometown USA, where they raised myself and my two brothers. In 1979 I married Laurence Brady, a Vietnam war veteran and Bronx boy. We and my parents decided that a home which would accomodate them in retirement, my paternal grandmother who was then 84 and living alone, and our future children who would be watched by grandparents while we continued to work, as an excellent plan for tomorrow and we were looking forward to becoming the American family of the 80's. In 1980 we purchased a home in Mahopac, NY, a hamlet 60 miles from midtown Manhattan. My husband and I commuted to work daily to the Big Apple and Dad retired from his job of 30 years with the post office. We were very happy. Previously purchased property was going to be sold and monies used to convert the downstairs into an apartment for my parents and grandmother. I was slinging pasta, boiling potatoes, holding down a managerial position, thriving as a newlywed, proud of my appearance, and quite content with what I had created. In 1985, our first son Mathew was born dead, revived and transferred by special ambulance to neo-natal ICU at New York Hospital. For anyone who needs a glimpse into the future, this unit looks like a set from 2010. Mat spent the first 7 months of his life in hospital where we were handed a very grim outlook for the future. Last year on Mat's second birthday he received a tracheostomy due to the fact that his throat muscles had collapsed. It has been a long haul. I have become jack of many medical trades, master of Mat's medical co-ordination. My son's care is constant and must be consistent 24 hours a day. He has a gastrostomy tube (feeding tube) for an eating disorder, an endocrine problem and is visually handicapped. His cerebral palsey and scoliosis affect his body's muscles and bones. His trach requires suction and high mist humidity and medications to open up his lungs. His ears are in a constant state of acute otitis media. He is a relatively new phenomena of medical technology and difficult for the lay person to comprehend. Do any of you question my sobriety in describing my sons extremely demanding life circumstances? Perhaps my calm affect is due in part to the fact that I have learned that I am not alone, for there is someone who has heard my sons silence - Margaret Mikol, from S.K.I.P. of New York. Parent Advocacy Groups such as S.K.I.P. of New York have helped me come to terms with the most wonderful person it has been my pleasure to know. Mathew is a beautiful boy - he is also a defiant individual who is short on patience, unwilling to remove his hand from his buzzer until you respond to what he is mandateing. The reward for this proper and timely response is a smile which lights up my world.

The intricasies of my 24 hour a day, 7 day a week job can only be compared to getting the annual budget passed. I have been thrust into a new managerial position, heretofore unrecognized and uncompensated. I have become my sons full time case manager, social worker, primary care-giver, systems laison and program designer. Corporate Headquarters for these activities is my kitchen counter. Filing and tracking insurance claims is monumental. I am running IBM from my kitchen.

At present, my husband's employee insurance through AMTRAK (carrier is Travelers) has $45,000. in benefits left for my son's medical care. He has then used $500,000 of insurance monies and the buck stops there. Mathew did receive New York State Care At Home Program in March 1987 after his trach. This is a good program, which has helped save some insurance dollars, however Mat's disabilities and HIGH TECH status cause him to use much more than the monthly cap. His pre-existing conditions do not allow him entre' to another good insurance program.

The medicaid system is at our option, however we are being told by providers that it is such a labyrinth that they do not want to accept it as payment. It is also our understanding that parental income must be kept within certain guidelines. Nursing coverage is vital to Mat's existance as none other than a professional can assist mom. When and if I have a nurse during the day, I tend to chores and many other family needs. When the night nurse is on, I try to catch up on much needed sleep. An agency provides R.N.'s on shifts - the cost is $32. an hour. When medicaid is introduced, I can work with the agency, however their profit margins do not allow them to offer a competitive salary to an R.N. working a medicaid case. I have heard of a wonderful pilot program called the FAMILY PARTNERSHIP, a model program working in the South Bronx. Services are paid for immediately, thus insuring that families and children receive what they need. Providers are happy with prompt payment and the fund is reimbursed by insurance or medicaid dollars.

My grandmother's bills, going Blue Cross/Blue Shield, medicare and medicaid, pose another whole set of clerical and filing problems. Grandma is 92 and in congestive heart failure. She suffers with diabetes, arthritis and angina. She is mentally alert. The day I was asked to this forum, she had suffered her fourth heart attack, as simultaneously my son's cardiac monitor began alarming, reminding me of my responsibility The hospital staff reported that grandma would much prefer to entertain the young, good looking interns than dwell on her disabilities.

The relatively new phenomena of these multiply-handicapped, technically supported surviving children AND the increasing number of the elderly living longer - coupled with the awareness of government that home is where the family belongs, has created a "catch up" situation, rendering me responsible for filling in all the gaps that everyone is scrambling to viably resolve.

Grandma's Home Health Aid is supplied through medicaid for five hours a day, five days a week. Whether this is sufficient or not I do not have time to dwell on. Mom, who suffers with emphazema and bouts of severe depression, only receives the benefit of my prayer that she will somehow hang-in for that is all I have the time for. My 68 year old father is cleaning cars in a car rental business to put food on the family table as our income is insufficient. My husband's blood pressure skyrockets. I am no longer gainfully employed, I no longer have credit. My pension funds and savings are gone. The property to be sold to finance the downstairs apartment was sold at a quick sale and a loss and the funds used to live on and pay debts. Our dream home and property are falling apart. We have gone from Yuppies to major financial burdens.

The dream of an extended family unit, taking care of themselves, for us, is dying. I have become trapped by my own plan. My competence and willingness to do it all has allowed a system to expect my working mandatory overtime. I am not alone - many women in varying socio-economic strata are in my position. I cannot fail... for if I do, my grandmother and son will be institutionalized and my folks will not be helped in their late years. The choice is to forfeit my son and family for myself. This is not a choice. It is an act of defeat. As I open my heart, my soul and my life to this representation, I call upon you to remember me and the growing number of families like mine, when considering legislation that affects my family, my child, my kind. We are women capable, willing and hungry to contribute to the well being of our society, if given the opportunity to be a part of it.

Chairman **Miller**. Thank you very much. Ms. Warnock.

STATEMENT OF DEBORAH WARNOCK, BROOKLYN, NY

Ms. **Deborah Warnock**. I am in a different situation because I do not, myself, care for someone. My mother takes care of my grandfather, who had a stroke about five years ago.

Chairman **Miller**. If we can move the other microphone over——

Ms. **Deborah Warnock**. My name is Debbie Warnock. I am 18 years old. I have a different situation than everyone else here. I do not, myself, take care of someone, but my mother cares instead. She cares for my grandfather who had a stroke about five years ago. The emotional strain and physical strain that is on the family is on the entire family, not just on the person that is giving the care.

You feel guilty yourself because you need your parents for you, when you know that they are needed with the person that needs the help which is my grandfather. You are afraid to leave this person alone. Therefore, you can no longer go on family vacations or just on trips by yourself because you are afraid to leave your grandfather.

My mother lived at my grandfather's house with my baby brother for approximately four years, three days a week, and it was hard to see her and my family and it kind of tore us all apart. It is hard financially because it was hard to pay tuition and the cost of living kept on rising and my mother could not hold down a job because of the situation.

Right now my grandfather has aides which live with him seven days a week, 24 hours a day. You can't leave them alone because they are totally incapable of taking care of someone who is in his situation. The aides really don't know what they are doing and it is very hard to watch them try and help him when you know they are incapable.

If there is anything that can be changed by what I have to say today, I would like them to have better care for older people who need it and that the aides could be better trained so they know how to take care of older people. That is it.

[Prepared statement of Deborah Warnock follows:]

Prepared Statement of Deborah Warnock, Brooklyn, NY

Dear Committee:

I come from a very close family. When one member suffers, we all feel the pain. Five years ago, my grandfather suffered a stroke. Our family has never been the same since. When this trauma first happened, we were all worried and confused about our futures. We were relieved to have him come home after a six month stay in a hospital and assumed because of his strength and determination, he would soon be well again. Since my grandfather was the only one in the family living on the first floor, my mother and her two sisters decided to care for him from his own apartment. Arrangements were made that each daughter live with my grandfather three days a week. We all assumed this would only be a short term arrangement and things would soon be back to normal. We were all disillusioned. This craziness lasted for more than three and a half years.

During those years, our home life was being torn into pieces. I was thirteen years old and I had to suddenly take on some of my mother's home responsibities. My Dad, my Sister and Brother and I had to share chores and learn to run a home without my Mother.

This was difficult because we all depended on her to always be there. We all missed her and our two year old brother who had to stay with my mother while she took care of Papa. We visited often but the three days she was gone a week seemed to last forever. A phone call or visit never seemed to be enough.

We felt guilty wanting her home when we knew that Papa needed her there too. We could never go away on a family outing without worrying about his welfare. He had never been dependent before. It was hard on everyone who knew him the way he used to be, to see him need help to do everything, even to go to the bathroom. He had always been strong and was always the first person I would turn to if I had a problem. It was heartbreaking for me to see him this way and I missed my old Papa.

Through the caregivers support group which my mother found within the community, the family learned to cope with many things. It helped Mom to obtain Medicaid for Papa. He now has a live-in attendant which allows my mother and her sisters to be with their families. They visit him every day. I can tell by the look in my mother's eyes, that she is relieved and a great burden has been lifted from her shoulders. Of course, there will always be problems because of Papa's impairments; but it seems to be easier now that our families have been reunited.

Through all these trying years, our difficulties have brought us closer together. It has made my sister and brothers and I more aware of the needs of the elderly and impaired and now have a deeper understanding of caring and sharing. My little brother, who is only seven now, is one of the best caregivers I know.

STATEMENT OF ARLEEN WARNOCK, BROOKLYN, NY

Ms. **Arleen Warnock**. I am Arleen Warnock. I am the mother of Debbie. I have often heard it called the sandwich generation, and I feel that is what we are because it is so difficult to care for the older person and at the same time when you are raising children, it is like I have two sets of children because when my father first had the stroke, my baby wasn't two yet, and I had three teenagers.

I know a lot of people said it is much easier because your children are older. I feel it was much more difficult, because as teenagers, you really have to guide and oversee much more than you did when they were five or six. You knew where they were at 8 o'clock at night when they were five or six. It was very difficult because it turned out to be a jealous situation thing between my father and the baby which you are constantly torn on who to go to first.

Where are your priorities? You can't turn back the clock and you can't say to the baby, well, stop growing now because I have to take care of my parent. It was very difficult and I feel they lost a lot by me having to be with my father. It was something I felt we had to do. We finally got my father on medicaid, but we have to oversee that because as Debbie said, the aides are not always capable of handling many kinds of situations and sometimes you get aides in that do not even speak English properly, which I think is very difficult, especially with my father and a lot of older people who have hearing problems.

If they can't speak English properly and can't be understood, my father doesn't know what they are saying. One time I remember going over constantly how my father was to be transferred, et cetera, and they kept saying, "I understand. I understand." And, five minutes later she called the police because she dropped my father.

The concern is are you going to get someone with any common sense at all, and will they be capable? Some are capable, but the majority that I found, they are underpaid and people that have nothing, I guess no skilled positions that they can hold down. So this is what they do. I think maybe if they were trained more properly and given better salaries, we would have more efficient people doing the job.

I think that there really has to be more public awareness of what is available in the community. I found a support group very helpful and I think it would be very good if there were more support groups in the area. My father is on Medicaid only because we found out through the support group that there was a surplus income plan which for four or five years we were not aware of at all.

They told us in social services in the hospital and at home that he made too much money and would not be eligible for anything to that effect. And if we wanted 24-hour care, because one time we had planned to just go away for the weekend and it would be $100 a day. We couldn't afford that.

My father belongs now to the Geriatric Center two days a week and that also I had looked into before he got on medicaid and that would be $100 a day. We could not afford that. If there was a daycare center that would care for the impaired, even a few hours, if people could get them there, not even if they provided their transportation, it would be something for the person to look forward to. That is all they have left.

Basically, they are immobile and they can't do anything. If they had some kind of communication with the outside world and if there could be some kind of even T.V. program geared to the impaired or the elderly, that would give them something in their life to look forward to. I think more than anything else, my father is very depressed and bored—he is not capable of doing anything by himself, and the depression that stems from that. It would be good if he had at least something to look forward to.

I think also there has to be more laws to oversee the elderly in hospitals. It is devastating and I could not even go into detail about what happens in a hospital if the family is not there to oversee things. You can sit in your own defecation for hours, and it is so demeaning and depressing and they turn around and say I wonder why the patient is depressed.

My father had therapy when he first had the stroke for five or six months and he was put in a wheel chair and they had said that mentally he was incapable of maneuvering the wheel chair and they kept practicing and practicing with him. As soon as he got home from the hospital, we got a new therapist, and he said the reason he didn't maneuver it was because the chair was too high and his legs were too short.

As soon as he got a shorter chair for a shorter person, my father was able to maneuver perfectly. So that was six months of wasted time and being told that he wasn't capable of doing it. Also, I think again, going back to the hearing, I have an aunt I cared for that just died a few months ago. In the hospital, her hearing aid broke and therefore, she laid there like a vegetable. There was no communication even attempted.

There has to be people to oversee this. I guess there are separate laws to care for small children that cannot answer for themselves. I think the same thing should be done for people who are senile or elderly that can't speak for themselves and say what they need. Basically, we need a lot more help. Thank you.

[Prepared statement of Arleen Warnock follows:]

Prepared Statement of Arleen Warnock, Brooklyn, NY

Dear Committee:

I feel it is very important that the general public be made aware of community services available to the handicapped,elderly and impaired. They should be more educated on what coverage medicare and other insurance programs will provide and what the difference is between medicare and medicaid. Families should be knowledgable in all areas of assistance before the services are needed so that in the event of illness or any hardship, they could make the proper decisions that are in the best interest of all concerned. My father is now on medicaid but on the surplus income plan. My family was ignorant of this plan and for four years, we were told by social workers that his pension was too high to have any but medicare services.

I believe changes have to be made in what medicare benefits allow for. For example, it does not cover the cost of a commode. Therefore, if you are poor or rich, you may have proper facilities but middle-class handicapped people must self-provide for this expensive item or buy a huge plug.

Medicaid applicants should not be made belittled by their interviewers. It is degrading to be treated by agency personnel who assume that everyone is lying and scheming to get services that many people truly need but are too proud to beg for.

Charges from services and companies, doctors,etc. should be examined more closely in order that monies are disbursed for the right purposes and into the proper hands. For example, my father belongs to a gereatric program two days a week. I believe the fee is $100 a day paid by medicaid. Is that not too high? Hospitals charge enormous amounts for items which are replaced too frequently without any regard to costs. My father has a nylon strip for the back of his leg attachment on his wheelchair. The wheelchair company bills Medicaid $6.00 a month rental fee for this piece. To date, this item has cost $288.00 instead of its actual cost of about $10.00

Under medicare and medicaid, we need more qualified aides. If workers were trained better and received a decent salary, we would get more people in the field with common sense. Also, because many elderly have impaired hearing, it is most important that aides speak English clearly. Many home attendants have accents that can not be understood by their patients. We believe having a home attendant with my father is far better then placement in a nursing home. He is able to feel some self-worth, we are able to visit frequently and, in general, it is a better environment for people who go thru stages of depression. The one drawback is the uncertainty when he has to change aides. Some attendants are very competent, compassionate people while others lack common sense and judgement in many situations that arise while caring for the impaired. Once, when my father asked for a grill cheese sandwich, he was asked if he wanted it with bread. Some have frequently dropped my father because of their inproper training in transferring clients from bed to wheelchair

There should be more support groups in the community. Only people caring for the impaired, elderly or senile can comprehend what others in the same situation are going thru. I have learned about services thru my support group and have mentally come to terms with my situation. The constant feelings of being torn between your feelings of responsibility toward your husband and children and toward your elderly relative leaves people totally drained and guilt-ridden. I have learned that I'm also a person with needs of my own and have a right to those feelings. One person can not stand alone and do it all. We all need help.

Chairman **Miller**. Ms. Lane.

STATEMENT OF NANCY LANE, SODDY DAISY, TN

Ms. **Lane**. I am Nancy Lane. My current family consists of myself, my mother and my sister and two small children. We are absent two members that we had seven years ago when my father originally had his heart attack and stroke. The heart attack and stroke left Dad a complete invalid. We originally placed him in a nursing home which they thought would be feasible at the time because they told us Dad was going to die.

The first visit we made to my father 24 hours after he was admitted, we found him naked, tied, wet and disoriented and this was a facility that was charging us $1,100 a month up front. We took a trip to the Social Service Office and strong language and forceful determination brought about a state investigation. That investigation did bring needed changes, but by the same token, we were still staying with him 24 hours a day.

We were afraid to leave him. We couldn't face the possibility that we would see him force-fed like we had seen people down the hall. Even though he was doomed to die, they told us that it was a matter of time. We decided to bring him home. We brought him home one day, my two-month premature son the next. We literally had two babies in the house.

We had a situation where time was limited, we were told, but over the next two years, my father and my son became each other's world. They went through physical therapy together, which we found out from my father was a deadend situation. But those two years were the best two years my son had ever had in his life. This was a child that had minor handicaps as far as education and physical abilities were concerned, but they grew together.

He brought my father back part of the way and my father took him even beyond that. Those two years were not what we considered maintenance care, which is what a nursing home would have given him. They have been loving care we would never have had those two years that he stayed in that nursing home.

It was a difficult situation, and at that time Dad was in a position where his finances helped provide the care and we live in a rural area and true enough, there are not a lot of support groups in that area. But the thing that is there is that our information system is pretty good. We managed to achieve the things at home that Dad needed to know.

His ability to retain that information was low, but ours wasn't. We learned how to take care of him at home. The only thing that we had was an occasional visit by a nurse to let us know that we were doing the right things. At the end of those two years when my dad died, his benefits died with him. It left my mother devastated, not just the emotional loss, but the survivor's loss of benefits were unbelievable.

She no longer had the free insurance that went through his work pension. She wasn't old enough for Medicare, but she had never worked. Her health was failing after two years of constant care for my father. And I was pregnant again with a second child, dealing with the handicap of the first, and we literally had to stay together to survive.

There were no options. We either pulled together or we failed. So a year and a half after my father died, I already had a second child, sick, not as sick as the first one, but again medical bills running into hundreds of thousands of dollars. And my husband could not cope with the responsibility any longer. So he left. There wasn't any time for him. My mother and my children came first. He couldn't share. He left, and his responsibility stopped and ours got worse.

My sister was our only means of transportation. I have a visual problem that doesn't allow me to drive. So she became my means of getting my kids to therapists and to counselors and things that they needed. I had a little boy that lost his grandfather and father within a matter of months. He was devastated. Counseling was the only option that we had.

We had a local Head Start organization that makes a sweep every year of our communities, and during their sweep they found our family. Now their efforts to get my son into the program, their directions that he needed as far as his educational direction was concerned brought me to where I am today. They taught him how to smile again. He was diagnosed hyperactive, attention span deficient, finding gross motor dysfunction.

They told me he didn't have to stay that way. They gave me the directions to go to find the help he needed and made me aware of the rights that he had to receive these things. True enough, my mother is still ambulatory, but barely. We can no longer leave her by herself for fear of her falling, hurting herself and not being able to get up. One of us is with her at all times.

Nursing homes are not an option any longer. The first experience was enough to tell us that there were no nursing homes that were fit to take them into because the supervision on this level is just unbelievable. The professionals are seen only at medicine checks and vitals checks, and the only people that you are in contact with are the aides.

As in the situation with my father, I had an aunt who was a little bit financially set, and she gave the aides extra money to make sure that they were available. We can't do that with my mom. We managed to survive on state benefits because there is no private support. My husband just didn't leave physically. He left financially.

His financial desertion of us put us in a situation where if it were not for the state benefits, as far as my children were concerned, they wouldn't eat, they wouldn't have medical care and I have worked all my life until my kids were born, but I can't afford to any longer.

The benefits I lose when I go back to work means that my kids don't eat. They might receive their medical care, but I no longer receive mine and the medication alone I take a month reaches over $100. In our area that is a week's pay. That doesn't leave time for utilities, rent and the things that we have to have.

If there is anything that I can help the committee to understand, there are a lot of local organizations that teach you how to help yourself, support those programs that educate us, give us the directions to go in and when we try to help ourselves, don't leave us on our own, don't take those benefits away that we have depended on for so long, give us a period of time to get on our feet.

Let us become active mainstream citizens again so that we can contribute for a change and that we are not just dependent.

[Prepared statement of Nancy Lane follows:]

Prepared Statement of Nancy Lane, Soddy Daisy, TN

I have long awaited the opportunity to voice my opinions on these subjects. I prefer to call us a double dependent family. The reason being we depend on the other for survival.

I am so grateful my great grandmother escaped from the "Trail of Tears". It enabled her to pass her courage on to help us fight our fight today.

The last several years have taught us to fight our health system, government agencies, illness, divorce, and death. The first fight came when my father suffered a stroke some seven years ago. The illness we could not fight, only survive. The nursing home though was another story. Only twenty-four hours after admittance we found him tied, wet, naked and disoriented. The fight with the facility that was charging us $1100.00 per month cost them much more. There wasn't enough tape or glue to put them back together and a state investigation brought changes needed by all.

The facility was a private one. It was beautiful to see and hard to digest. The staff were all well-paid, trained professionals. They were seen only at medication time or vitals check. The cleaning staff and aids were much more accessible. To insure his needs were met, and quality care was given, a family member stayed with him twenty-four hours a day.

Being unable to feed himself would have found him starving had it not been for constant attention. We gave extra money to the aids to prevent force feeding and keep them available when needed.

Around the clock family sitting convinced us, dying or not, home was where he belonged. So home he went. If only our society would practice loving care instead of maintenance care, the benefits would be incredible. We brought home my two month, premature son and father within a day of each other. My father did die, but only after two years of loving and fighting and growing which we would never trade for a thing in this world. I truly believe those two years we had would never have happened in that nursing home.

His death wasn't just an emotional loss for us, it nearly devastated my mother financially. The survivor loss of benefits were tremendous. No free insurance with full coverage, or pension, and only a portion of the Social Security was all she had. So we pulled together. With another baby on the way and a sick two-and-a-half year old already here, we loved hard and fought hard to keep it together.

I had a responsibility to my own children and to my mother as well. Grief drifted away on the wind, for living leaves little time to stand still. My husband had difficulty in realizing everyone's ability to make it depended on everyone staying together. So eighteen months after my father's death and a year to the day after the birth of a small, beautiful, but sick daughter was born, he left. The responsibility became so much and my time so divided he walked away. His responsibility decreased and our problems grew.

The next few months were some of the hardest of my life. My son was diagnosed as hyperactive and attention span deficient. This coupled with the loss of his father nearly destroyed a beautiful little boy. Trying to cope with this almost beat me.

Little boys and girls have to eat, need new clothes and shoes, so state aid came to our rescue. The provider agencies were my enemy as well as my salvation. I had always worked and been independent. Now I couldn't afford to. I didn't have the time or the benefits to spare.

Then Head Start found us and a door finally opened for us. In the beginning we were both shy about going. The struggle had wrecked it's toll on us. I began to see hope when the teacher coaxed smiles back into my son's eyes. They gave me a direction to reach for and I did. With their help my son gradually came off medication for the hyperactivity and counseling with professionals gave us back our confidence.

Head Start helped us help ourselves grow. They provided not only the educational direction for my son, but they gave me a map on how to get there. Staff advised me on rights and how to get the services in the public school system he needed. Our local public mental health clinic helped get the diagnosis to classify him educational handicapped.

The one thing I didn't realize was that I had learned to fight within the system instead of against it. Within another year Head Start opened a door to me by election as Center Chairperson.

During the next school year my sister became involved also at the center level and my mother began helping from home with any project we brought home. The program not only helped boost our ability to provide things needed for our family but began to let us give our own help to others.

This past school year found me as elected chairperson for the Policy Council, representing the whole program. As a direct result of these growing changes I am now in a position to pass my success on by hopefully testifying to the Select Committee.

To say that things have changed miraculously would be misleading, but there is hope. My exhusband is some $12,000.00 behind in support payments and millions of dollars behind in love and attention payments to our children. My mother's health isn't as good as it was and we stay close to home more than we did. We still barely make ends meet month to month. On the other hand my son has cut his resource time in half and is successfully mainstream educationally, making good grades. My daughter is functioning on a level several months above her age group. The educational success is directly a fact of their Head Start experiences.

It would be nice if I could face joining the work force again, but the loss of benefits and the complications of child care and health care still make me and my family dependent. Dependent on the agencies providing the necessary assistance for survival.

If there are any suggestions I might make, it would be to help us help ourselves. Look at levels of local and state support systems to recoup us to private support instead of public support. Find an incentive to those families to choose to help themselves by taking care of their own. Help those of us who want to succeed by supporting those local programs who teach us how, but above all enable us to know that when we try and fail to help ourselves that our government will help us, not penalize us for trying.

Ms. **Morella**. I appreciate being able to come here to the Select Committee on Children, Youth, and Families on the important issue that I have already heard articulated by these very eloquent spokespeople. I am a member of the Select Committee on Aging, and we have been discussing and given considerable time to this whole concept of care-givers in our society. Truly, one of the greatest needs and challenges is what we have today at your hearing where we are talking about double-duty care-givers, those people who have responsibility for caring both for children and aging parents.

I am pleased to have the opportunity to introduce to you the final member on this first panel, a gentleman who is a constituent of mine, James McEuen of Bethesda, Maryland. He has two children, aged five months and seven years and also has an aging mother who is in a nursing home. Thus he is trying to care for his children while at the same time taking care of his elderly mother.

As his testimony will indicate, this is not a typical situation, but it is a very stressful one for all members of the family and is one shared by others in the country. His testimony and the dilemmas facing the other witnesses today do represent many families in our country.

A number of legislative initiatives and proposals will be looked at by this committee and, Mr. Chairman, I look forward to working with the committee in any way that I can. Again, thank you for holding this hearing.

Chairman **Miller**. Mr. McEuen.

STATEMENT OF JAMES E. McEUEN, BETHESDA, MD

Mr. **McEuen**. Mr. Chairman, distinguished members of the Select Committee.

I appear before you today to share the painful experience of one family of the sandwich generation. I would like to thank you for the chance to make sense of this past year and to look up and think of the future as I ask each of you to do, to think of the future as I range over my prepared testimony, as I range over three generations.

I would like to thank Connie Morella. When my father died last St. Patrick's Day, 1987, I called the Office of Personnel Management. He was a retired civil servant. They told me it would take three months for me to get the forms to apply for his pension, the survivor's benefits for my mother, three months just to get the forms to apply.

She had to go into a nursing home immediately, as soon as we could do it. What could I do? I called my Congresswoman, Mrs. Morella. She had one of her aides call on OPM and we got the forms in three days. It got some kind of a bullet on the file and my mother, thank God, got her pension check, I think, within three months. During that time she exhausted all of my father's life insurance benefits.

That is one little side story. This is a Washington story. It is a middle class story. We are lucky to have the resources we have, but we are not only lucky. We have worked hard for them for two generations. Those resources are inadequate for me to put a patient in a nursing home. I am a bit ashamed that I would complain when my fellow witnesses are going through such an ordeal. We are going through an ordeal, too, and it is not enough even with the GS-15's pension to pay a survivor's stay in a nursing home.

The first effect of the sandwich generation is the extreme isolation. We dipped into the well of our financial and inner resources, at times to find it not only dry, but also to feel its walls pressing close around us, alone and in the dark. Whatever legislative family care measures you consider, I think that the need for information is paramount. You must insure that this need is ameliorated for the beleaguered care-givers.

In 1987 in the nine months of human gestation we lost my father suddenly to a burst aortic aneurysm. We lost my wife's mother on June 3rd to cancer. On April 8, three weeks after my father's death, we institutionalized my mother in a nursing home. At least for 25 years my mother suffered from central nervous system disease, a slow degenerative illness like multiple sclerosis that affects the motor functions and speech, and she also suffers from emotional problems that have led to periodic violence and attempted suicide, and for the past 15 years she has been wheel-chair bound.

That same year, on November 23, we gave birth to our second son. Thank God, both of our children are healthy. I don't know what we would have done if we had had disabled children. These events struck when our own full-time, two-career, day-care life was already stretched perilously thin.

Let me describe the three generations. I was born in this city, the eldest of four children and was raised in Silver Spring, Maryland, in Montgomery County. My father was a GS-15 U.S. civil servant when he retired in 1973. After college, marriage and my graduate degree, my wife and I returned to the Washington area and took beginning jobs in publishing here.

We both are 40 this year, our 20th anniversary. As many of my generation have found, it took longer for us to get started. There was this article in the Reader's Digest that prices have gone up 400 percent in the last ten years. We delayed child-bearing for economic reasons. In 1981 we bought our first home. We couldn't even afford the neighborhood I grew up in. We had our first son on May 7, 1981. We were 33 then. We needed two full-time incomes plus regular supplemental free-lance income to survive economically.

We improvised day care for my first son. For my wife it was 18 months of a combination of unpaid maternity leave and part-time work. My mother-in-law commuted regularly out of her own expense from Red Bank, New Jersey, out of love for the first grandchild in the family. She spelled my wife for one day, actually two days when she went back to work part-time.

For eight months of that 18 months, I spelled my wife for another day. I guess I am honored to be the only sort of eighties male care-giver here today, and I eat quiche whenever I can get it, frankly. I was able, as a writer and editor, to take my work home and to care for my infant son to give my wife the time to go back to work.

After these 18 months, we found day care in our neighborhood. It was not through the Montgomery County licensed referral system. We tried that. The licensed home day caregivers were spread out.

Some of them seemed inadequate. We found it through our elementary school. We were wonderfully pleased with our day caregiver.

My eldest son was lucky to be in an extended family day care situation. That is what it was like for him. In 1984 I changed jobs. We moved and traded up, the same sort of thing that many in this area do. We then found full-time day care for our son in a day care center that offered after school care in the elementary school in the neighborhood. It was the only day care center with busing arrangements to that elementary school.

We could barely manage our higher mortgage and the child care costs. We scraped to refinance our mortgage to get some relief. My first son continued in that day care center until 1987 when my wife, after eight years at her job quit so that she could care for my eldest and the new baby, also to keep up with the mountainous paperwork it takes to manage our own family, help with settling my father's estate, help her own father get over the grief of losing his wife, and the incredible amount of paperwork to keep my mother's care going.

In 1986 we learned of my mother-in-law's cancer. We were trying to give care and solace to her and my father-in-law during her surgery radiation therapy and her intense pain when my father suddenly died. He collapsed trying to help my mother up in the bathroom where she had fallen as she frequently did in caring for an operable prolapsed uterus, as well as other disabilities.

My father handed my mother the telephone and she called my sister. He collapsed again. My sister called an ambulance. Before I could get to the hospital, I had to pick up my son at day care and my wife downtown. My father was dead. I never got to say goodbye to him.

We then had to immediately find some kind of care for my mother. We didn't know where to turn. We tried through agencies in the phone book to get in-home registered nursing care for her at incredible expense—$200 a day or $250. I forget what. My mother scuttled the whole thing because she was afraid of strangers coming into the home for the night shift.

At that time, at the same time we were filing claims, finding lawyers, notaries to get the power of attorney for my mother and her renunciation of the executorship of my father's estate—she can't handle that kind of stuff and we don't want to have her declared incompetent and strip her of all dignity—we were comforting my mother and working out rivalries among four children, arranging for the funeral and burial, visiting nursing homes trying to locate one she could afford and that was clean and caring, all the while my mother-in-law was dying of cancer in New Jersey and my father-in-law was becoming dangerously depressed. We hired a social worker out of the insurance money, which paid off quickly, to help us with all of these arrangements. Her name is Barbara Kane. We read about her in Newsweek. She specializes in helping out-of-state families with parents in the Washington area to arrange for care here.

Her services have been invaluable. We found a nursing home for my mother, luckily one that was clean, small, home-like, church affiliated, run by the Adventists, called Brook Grove, in Olney, Maryland. Her government pension doesn't cover her expenses there.

She falls short about $275 a month. To make up for that shortfall we had to sell the house in Silver Spring.

First we had to repair it. It was in chaotic disrepair. Both of my parents were incontinent. The basement, the recreation room downstairs where I had watched TV as a child was piled to the ceiling with debris. They had rats. It was not a pretty scene. We borrowed money against the sale of the house, repaired it and finally sold the house this past January.

That is all of my mother's assets for the rest of her life. We are trying to manage them well for her. One of the effects of being in this position of doing double-duty, of living in the middle of the sandwich, my wife and I have not yet properly mourned our lost parents. We haven't had time. We were repairing my mother's house and we have been managing her personal affairs instead.

We finally found all the records to settle my father's estate. In effect, he died penniless. He hadn't paid his taxes for two years and all of his money, 40 years work for this government, will go to the IRS for back taxes. My mother will get nothing of it. She paid for his funeral herself out of her limited personal funds. We have been paying bills for two households, and the time with my older son and care for the baby, with all that, we have little time for ourselves.

Our marriage, thank God, is strong, and we grow together through these changes. My mother calls at all hours for us to drive the 45 minutes to bring her mouthwash and other incidentals not provided in a nursing home. These are the facts of our daily life, little things that become big things because they are so constant.

She wants us to take her out, to do her laundry. The laundry at the institution ruins her few good dresses. She has to see a gynecologist and ophthalmologist. There is no transport. I am running out of annual leave. I have to take annual leave to take her to the appointments. The county runs a shuttle business, but they can only use it once a month for some bizarre reason.

My wife has sacrificed her career for our children's welfare and our family's welfare. We have no financial safeguard ourselves. I have foregone rapid career advancement because I don't have the time to put in the extra hours and get the extra education. My weekend time with my own kids is limited because of my mother's needs in the nursing home.

I will mention my last point. Our older son's last year of day care in 1987 was marred by the effects of an apathetic and negative primary caregiver. The center was fine. It had the climbers and the swing sets, but it didn't have a dedicated caregiver for my son. It affected his self-esteem severely. We considered going to see a psychologist. I didn't think it was possible for a four or five-year-old to be severely depressed, as I had been going through all the changes that I had gone through, but this subjective kind of thing, a caregiver who sits and barks orders affects children. It affects them deeply.

He had trouble in kindergarten because of it. This year out of day care he has blossomed. He has many friends, and he is self-confident and an excellent student, and he has been ill only once. He was ill constantly with strep throat before. It seemed that it was an antibiotic resistant strain. We would go through three different antibiotics before we could knock it out. He had head lice about every three weeks. The caregiver blamed him as being the lice carrier, a kind of typhoid Jonathan. It was endemic in the center. My wife was pregnant and she couldn't use the lice shampoo. These are little things, but they take their toll.

We are fine now. We are stretched thin. We are coping. We are lucky to have the resources that we have. I would urge you to consider all families in this position regardless of income level. We need in this country a safety net that will catch everyone, not the poor only, not only the middle class, not only the affluent. Everyone has children and everyone has parents. This society is brutal to the very young and the very old and it has to change.

We are the baby-boom generation. I have educated myself on this issue. We have the numbers, folks. As soon as we wake up to this, as soon as my generation, brothers and sisters, go through this, they won't forget it. As soon as they realize that our society is inadequate in giving the kind of assistance that we need for the American family to survive through the coming decades, I think they are going to vote this issue and vote it with overwhelming numbers.

There are going to be some careers ended here, and new careers will begin. Thank you very much.

[Prepared statement of James E. McEuen follows:]

PREPARED STATEMENT OF JAMES MCEUEN, BETHESDA, MD

Mr. Chairman, distinguished members of the Select Committee, I appear before you to share the experience of one family of the "Sandwich Generation"--a middle-class suburban, local family whose members have done the expected things to succeed but who have seen their productivity, creativity, and expectations curtailed because of providing simultaneous child, infant, and elder care with little information or support. Whatever the legislative measures you will consider--and they must be incisive and far-reaching, to include, for example, uniform tax credits, employee leave, and quality standards for family care; consolidation and improvement of coverage of Federal family-care programs and family-care assistance to the states; family-care incentives to private firms; even extension of universal public education downward to cover 3 year olds, and Medicare to cover long-term nursing care--you must know that loneliness and lack of comprehensive information about family-care options are the first pressing effects of being "sandwiched." Ensure at least this care for the beleagured caregivers.

At times we have dipped deep into the well of our financial and inner resources only to find it dry--more important, also to feel its walls pressing close around us, alone and in the dark. I stress family care, for the needs of the very young and the very old are similar, as is their shocking, barbaric, dehumanizing neglect by our society. Some years ago it was said that national family-care policy would destroy the American family. Preposterous bunk. It is precisely the lack of such comprehensive policy that threatens to destroy the American family now, to unravel slowly the central knot of our social fabric--a generation of children with tenuous self-concepts and attachments to basic social institutions in an environment of easy drugs and heightened global economic competition; a rapidly aging older generation that faces near certain impoverishment as its life expectancy increases. And I emphasize uniform measures because all families with young children or infirm, aged parents need help, regardless of income level.

In 1987, in the 9 months of human gestation, we lost my father suddenly, on March 17, to a ruptured aortic aneurysm; we lost my wife's mother--our own sole emotional caregiver--on June 3 to lung cancer; on April 8 we institutionalized my mother--who for at least 25 years has suffered from central nervous system disease, a slow degenerative illness like multiple sclerosis that affects motor function and speech, and from emotional problems that have led to periodic violence as well as attempted suicide, and who for the past 15 years has been wheelchair-bound; and on November 23 we gave birth to our second son. These major life events struck in succession when our own full-time, two-career, daycare life was already stretched perilously thin. Let me describe our life before 1987, give additional description of that year, and conclude with the effects on my family.

I was born in this city and raised in Silver Spring, Md.; my father was a GS-15 U.S. civil servant at his retirement in 1973. After college, marriage, and my graduate degree, my wife and I returned to the area and took beginning jobs in scholarly publishing. We are both 40 this year, the year of our 20th anniversary. We delayed childbearing for economic reasons. In 1981 we bought our first home, in Silver Spring, but we could not afford my childhood neighborhood. When we were 33 we had our first son, on May 7, 1981. We needed two full-time incomes, as well as regular free-lance work, to survive. We improvised childcare: 18 months of a combination of extended unpaid maternity leave and part-time work for my wife; regular commuting from New Jersey for my late mother-in-law; 8 months of one-day-a-week "paternity" work at home for me, during which time I also did massive overtime assignments to make up my wife's lost income. After 18 months we found home daycare in our neighborhood--not through Montgomery County licensed referrals, which we screened, but through the local elementary school. Our caregiver, with whom we were quite pleased, became licensed during the time we used her services.

In 1984 I changed jobs to increase my salary, and we moved to a more expensive neighborhood for its well-respected public schools. We found full-time daycare for our son at a daycare center that offered after-school care in, and busing to, our local elementary school. We could barely manage the higher mortgage and child-care costs, and we scraped to refinance our mortgage in 1986 to gain some relief. Our son continued in daycare until the birth of his brother last year, at which time my wife resigned her position after 8 years with the same employer so that she could be the caregiver to our children as well as keep up with the mountainous paperwork required for my mother's care. We sacrificed 25-30 percent of our gross joint income, but that reduction became only 10-15 percent after we factored in double childcare and increased "marriage tax" and working expenses--a bargain, given the unquantifiable physical and psychological costs from the stress of four daily schedules and doubled parental guilt.

In 1986 we learned of my mother-in-law's cancer. We were trying to give care and solace to her and my father-in-law as best we could during her surgery, radiation, and pain when my father died. He collapsed trying to help my mother up from the bathroom floor where she had fallen--as she frequently did in caring for an inoperable prolapsed uterus--regained consciousness long enough to give my mother the telephone, then collapsed again. My mother called my sister, who came from work and called an ambulance. Here is an example of the tolls of "double duty": I was sick that day; before I could get to the hospital I had to pick my son up at daycare and then my wife at work downtown. My father was dead by the time I arrived; I never was able to tell him goodbye. Next, on the day of his funeral, we learned of my wife's pregnancy.

Before my father was buried we had to find 24-hour supervised care for my mother, who could not be left alone for even a few minutes. We anticipated this, as surely as we had been broken as a family by her emotional swings and violence over the years. At first we children took shifts. My mother at the last minute refused complex arrangements for private in-home nursing--incredibly expensive--for fear of strangers at night. We finally hired the Spanish-speaking housekeeper-companion and her family to move in--an unreliable and disruptive arrangement. At the same time we were filling out insurance and pension claim forms, finding lawyers and notaries to obtain my mother's power of attorney and executorship of my father's estate, doing the daily shopping, juggling babysitting for our and my siblings' children, comforting my mother, working out old sibling rivalries, arranging the funeral and burial, and visiting nursing homes. All this at the same time my mother-in-law was dying and my father-in-law was becoming severely, dangerously depressed.

We thought we would go mad. Luckily, out of the blue, I remembered a Newsweek article about a local private social worker, Barbara Kane, who helped out-of-town children care for their aged parents here. We hired her immediately to help us stay sane and find affordable, Medicaid-certified nursing care. Her services have been invaluable. After my mother was admitted to Brooke Grove Nursing Home in Olney, Md.--a small, clean, church-affiliated, home-like, moderately priced nursing facility--we had to sell the family home to supplement her civil service annuity, which falls short of the monthly nursing home cost by about $275 a month, excluding the social worker's fee. We borrowed $15,000 in a second trust against sale of the property to repair the chaotic neglect of my parents' last years there. We settled on the sale in January 1988.

What is double duty--life in the sandwich--like now? My wife and I have not yet been able to mourn our lost parents and put our grief to rest properly--we had been repairing and selling my mother's house and managing her complex financial affairs instead. We are still searching for records needed to close my father's estate. Paying bills for two households, time for my older son, and care for the baby leave little conjugal time for us. My mother seems settled now but is volatile and has had two incompatible roommates and enough friction with the staff to warrant a multidisciplinary conference. She calls at all hours for us to drive 45 minutes to bring her mouthwash and the incidentals not provided in a nursing home, to take her out, to do her delicate laundry. When we both were working, it was a child's illness that would suddenly wipe out our precisely orchestrated schedules; now it is any specialized medical care for my mother. She must see a gynecologist and opthalmologist regularly, and I must take vacation leave to transport her. My wife has sacrificed the satisfactions and income from an established professional career for our children's welfare. Her free-lance editorial business has dried up, and with it our financial safeguard. I have sacrificed rapid career development because I must take frequent annual leave to attend to my mother's needs and cannot undertake necessary further academic training at night. I have delayed pursuing a promising parallel career in creative writing and had to resign a leadership role in my church, in which I have become inactive. We are heavily in debt and cannot adequately save for our sons' college education. Any inheritance for the grandchildren from my parents' lives will likely have been used up by my mother's nursing care.

Our older son's last year in daycare, 1987, was marked by the effects of an apathetic and negative primary caregiver, by the center's financial and staffing difficulties, by minor injuries from inadequate playground supervision, and by constant bouts with head lice and strep throat. He had behavioral difficulties in kindergarten serious enough for us to consider taking him to a psychologist to help improve his self-esteem. But this year, out of daycare, his self-confidence has blossomed, he is an outstanding student, and he has been ill only once. Our 5-month-old baby, cared for at home by his mother, is thriving. We see the rightness of our choices in the happy smiles of our sons. With God's help and our own continuing strength, like them we too shall thrive.

Thank you, Mr. Chairman and members of the Committee.

Chairman **Miller**. Thank you.

Let me thank you for sharing your stories, if you will, with us. When I sit here and I listen to you, each of you has told a story and you have reflected all of the values that very often politicians give speeches about and we say we want in the American family. Values such as a sense of obligation, a sense of value for our parents and our children, and maternal and paternal decisions about our children and about other members of our family that we say we want to see families exhibit and that we like to believe that we exhibit in our own lives.

What is interesting, if you read each of your histories, and as I listened to you, each of you has subsidized those values in a rather dramatic way with the loss of a job, the loss of a spouse, alienation of your children—and with your own well-being, which must include incredible fatigue in terms of your daily feelings. What your testimony calls into question is whether or not that is really correct, whether that is really the way it should be.

You know, we have information here for the members which suggests that the average annual loss in income to families that engage in these kinds of activities is about $20,000 a year because people are forced into dropping one source of employment or income. As Ms. Lane pointed out, you really don't have the option of going back to work and you worked every day until this crisis.

Really, that is a penny-wise, pound-foolish policy of the government. Mr. McEuen, you discussed your mother-in-law coming down to provide child care for you at a tremendous commuting distance and what that saved in terms of your family income, which kept the burden off of the government for a whole lot of services. That calls into question this mix of services that are needed for families, respite care so you can go out into the park and scream or not get angry at your children or you can spend time with your children away, or also just to have the luxury of taking a deep breath and thinking this thing through with your spouse or your children or your parents.

What that really means in terms of savings to us, since you obviously are willing to take on this burden, is really quite remarkable. You reinforce the notion of family that we say we want. I question whether we have to make victims out of people in an effort to do that.

Let me ask you quickly, what would be the one service that you would think, and I know you obviously described a multiplicity of circumstances where different things were needed, but what would be the one service that you really think would make the biggest difference in your daily life.

Ms. Brady, you described a 24-hour day, where you are either there or on call in your residence. What about you, if you can speak up?

Ms. **Brady**. I don't think that I could come up with one major solution to all of the problems. Looking at it from the perspective of my son, my mother and my grandmother, some kind of consolidation is necessary. Her care is, as I said. We are going Blue Cross/Blue Shield, Medicaid, Medicare. Why isn't that just one thing?

In my son's case, for me, for what we are going through, if there were some type of insurance policy that he could have that would help him, because we are running out of insurance dollars and that only means more devastation to my family. That is the only thing that I can say would work for me. I don't know how that works for everyone else.

Ms. **LANE**. I am not sure that I have any suggestions, other than those that I made about helping us to help ourselves. We are a success story in a sense of the word. We are not financially set. It is still very difficult, but we have weathered the hardest part of it. We are successful in that we have managed to put everything in a little compartment.

There is time for each thing, for each member of the family, and this has been an ongoing situation for seven years. I still have a basically healthy mother, but she is reaching a point in her life and I had forgotten when I dealt with the situation with my father how difficult it was to provide medications, the insurance, the benefits that are so tiny compared to the cost of the medical.

It is unbelievable. She has been sick for three months. She is losing her ability to walk. She is waiting for her medicare to take effect the first of June before she goes to the doctor. She doesn't have the benefits together. You see too many situations where you have one spouse pass on and the survivor benefits, losses are unbelievable.

We are a younger generation in that how I deal with my children. The options are there; the help is there. We are lucky in our area. We have a lot of good support through a lot of different organizations that give us the directions to go. We are still very, very, very, detrimental to our "gray" population, though. They are increasing, and I hope when I reach that point, I am not going to have to worry when I am going to have medication, the money together to see a doctor, and I am not sure that public health systems are designed to help those people.

They suffer so much in terms of illness. That is what aging is. There is correct help and more help to prolong that life, but what is the sense in prolonging it if you need to go to the doctor and you can't? So that is, to me, the biggest problem, the health system in general, the funding and benefits. That makes it difficult. That is where the drain comes on the whole family. If you can provide that health cost, you have got everything else licked. You have got your own support, your own love. The health cost is what kills you.

Chairman **MILLER**. Deborah, from your perspective?

Ms. **DEBORAH WARNOCK**. I think the most important thing that you have to work on is keeping the family together and close. If there was more support groups that help you let out your feelings so you can just worry about loving your whole family because once you lose love, it is just not even worth living because if I had to worry about taking care of him or having my grandfather put in a place where there wasn't love, I don't think I would want him to even stay alive.

You have to think about when you are older, who is going to take care of you and if you are going to be cared for with loving care or if you are just going to be cared for. Maybe you won't even be cared for the way things are going now. So just you need love, that is all.

Ms. **Arleen Warnock**. When I was originally taking care of my father and my sisters did it also, and thank God I had someone to share that with, but, I think at that time, I think it would have been a great idea if I had an hour, one hour out of 24 hours just to be able to walk around the block and say I have no responsibilities at this moment.

But now that he is on medicaid and we constantly oversee it, it is in our minds and constantly an emotional strain that we have to overlook what the aides are doing.

If I could know, there was someone capable for him, that would be the most important thing.

Mr. **McEuen**. I remember the complete lack of information of options. What I would want would be some kind of centralized, maybe computerized, comprehensive family care clearinghouse, a family care network that was advertised, funded to the states, so there would be one in every county. Call it a family care network. You have trouble. You call them, and they would have a social worker and an administrator who would know about all the options and programs. They would have a legal aide and they would have someone maybe who knew the health system. So in one place, whether the family crisis was with our parent's generation or with our own children, you would know right away and you would go to this one place and they would tell you what all the support arrangements might be.

They would have lists of the nursing homes and day care centers and you wouldn't have to spend the days on the phone, not hours, days, trying to make all these arrangements. I think that is what I would want.

Mr. **Coats**. Mr. Chairman, I really don't have any questions.

I want to thank the panelists for appearing this morning and sharing their stories with us.

You represent millions of people in this country and across the world that have been trying to deal with the age old problem that has been with mankind as long as mankind has been in existence, and that is caring for one another and the family, the difficulties of doing that, and what support might be available.

I thank you for your contributions.

Chairman **Miller**. Mr. Durbin?

Mr. **Durbin**. I have to concur with the chairman's conclusion that what we have heard in testimony this morning suggests that there are an awful lot of unheralded heroic acts going on day-to-day. Thank you for coming in today and giving us your experiences and perhaps reminding some of us who feel that we are under pressure that we aren't even close.

One of the things that I find curious is the continuing suggestion that nursing home care is so inadequate; that so many people who have been through this experience with their elderly parents or relatives come away from it saying this is not even a good place to go and die, let alone to consider living.

Most of that is the subject of state regulation. We have tried at the federal level to establish some minimum standards through Medicare, but has any one of you found a nursing home facility in your communities that is the exception? Is it so expensive that it is prohibitive?

Mr. McEUEN. It is not—it is midway.

I mean my mother could not afford some of the better ones, better in terms of equipment and activities and all of that sort of thing. We found a small church affiliated nursing home in Olney, Maryland, called Brook Grove Nursing Home. It is affiliated with the Seventh Day Adventist Church, which has a long tradition of care giving. We sought them out. They run a couple of hospitals in the Washington area.

They manage their facility as if it were a home, someone's home, and they care about the people. It is an individual kind of care. I mean the person doesn't become a slab of meat however incompetent they might be.

Mr. DURBIN. If I might interrupt a second. My mother is about 80 years old. I am listening very closely to what you are saying. I am told in many of these nursing homes, that after a period of five or six weeks that a person can become so dependent on nursing home services that there is no independent living left, no decision-making, no involvement.

Is the example you are describing different?

Mr. McEUEN. My mother's——

Chairman MILLER. The students who came in, you are more than welcome in here.

[Discussion held off the record.]

Mr. McEUEN. My mother's situation is double-edged. She is alert enough to know what is going on. Her movement is the problem. She can't manage. Her ailment is a deterioration of the insulation of the nerves. The nerves short-circuit, and that is the problem. We have tried to—we have hired a social worker, a private social worker that cares for her and helps her write letters at our own expense.

We also have a phone in her room, and believe me, that is a worthwhile expense. She is calling constantly. It keeps her active. It keeps her independent. She never—because of her disability, I mean she couldn't cope—so I don't know what you mean by independent living. She couldn't hold a job or fill out taxes or anything. Short of stripping her of her last dignity, this is the arrangement.

Mr. DURBIN. An alternative such as home health care doesn't sound practical in her situation.

Mr. McEUEN. We found there was too much variety, too much variety of incompetence in care givers, the people coming in.

Mr. DURBIN. People coming into your home.

Mr. McEUEN. Yes. The training, some people are good and some people are thieves.

Mr. DURBIN. Perhaps I am mistaken, but it strikes me that home health care could be, in the right circumstance, more effective; and as you described, more ideal.

Mr. McEUEN. My experience with both ends of the aides spectrum is that, with a good care giver, home day care is ideal. It is like an extended family. It was great for my son. His problem started when he got into an institutional day care center; the same, I think, for the elderly. If you can arrange it—we couldn't—but they made too much money for medicaid.

It would have to be private care nurses coming in or private nurses from agencies and they are like temporary agencies. So there is constant turn-around and they are allegedly bonded but you have no control. The other thing is to try to hire a long-term person as you would, you know, a housekeeper or something, whom you could trust and you would have the one-on-one. But you know, how do you find people like that?

Mr. **Durbin**. Thank you very much.

Chairman **Miller**. Mrs. Boggs?

Mrs. **Boggs**. Thank you very much, Mr. Chairman. I suppose that the care of the elderly, to me, is enlightened self-interest. In the care, home care institutional home care, I have had a long experience. I ended up being the only child of four women, all of them had been married at least twice, and I went through a great deal of caring for them in my own home, and also then eventually having to have some of them go to nursing homes, if you will, that situation.

I think that, as you have discovered, that with the Seventh Day Adventists that when you have a care center that is run by very good board of governors of nonprofit organizations, it provides the best possible kind of independent living, loving care and where they make the people who are there take some responsibility in a voluntary way and to care for each other as well, so that I agree very much with your assessment of that kind of home care.

Let me ask you, in the home situations, I don't know if you have experienced this, but they have found in England, for instance, that the incidents of young people resenting the care that their parents have to give to elderly grandparents has caused a great deal of family violence in that regard, so much so that they call it "Gram-slaming."

Have you had any experience in this regard.

Mrs. **Arleen Warnock**. Just in my experience and my sisters who have children, too, I found it made them better people. They definitely felt guilty for the fact that they wanted their immediate parent home, but they realized where the responsibilities were. I think they are more aware of the needs of the elderly now. Even my son, when my father first had the stroke, I think he was 15 or 16. He went to the hospital and he learned from the therapist how to transfer. If I need help getting him and out of the car, he would be there to help me where my husband wasn't.

Some people can't cope with a stroke patient. My 16-year-old was the person instead of my husband who helps me in those matters. I found that my nieces are also much more caring people. I found the opposite happened.

Ms. **Lane**. So did I. I don't have children that are geared to that age myself, but I have three older brothers. This is a situation where we were talking about the women being responsible for the care. It usually happens that way, but I have older nieces and nephews and they would come and learn how to take the blood pressure and vitals and they would spell my mom for a couple hours on Sunday morning and we would all go to church.

If I had to take the kids to the doctor, I would have an older niece and nephew sit with them. They learned what living was about. I don't see that situation, and ours is not a unique situation. I know a lot of families like ours. And the second or third generation, better still, is learning that this type of care given at home is much preferable to shuttling them off to a nursing home, and let's forget them and make our Sunday visits. They learn the different style of life.

Mrs. BOGGS. I thank all of you very much and I think that this committee has tried to become a clearinghouse and certainly the suggestion of having some central clearinghouse for services, types of services help that is needed, is a very valid one.

I do believe that what you are doing and what this committee has done and the witnesses who have come here previous to your visit have so highlighted the problem that we now find, for instance, the New York Times of last Sunday, where they have the world and they have the nation, the nation, the whole page is devoted to care, to child care, to the care of persons who need it in family settings and institutional settings.

To elevate the problems associated with the needs, to that kind of public scrutiny is really a very valuable service. We thank you very much for doing that.

Mr. WORTLEY. Thank you, Mr. Chairman.

First of all, I would like to ask unanimous consent to enter into the record an opening statement. I don't think there is anything more beautiful than family love and certainly adversity brings us all closer together. Stress sometimes just about reaches the breaking point. We have had a few experiences of our own. I couldn't help but notice your comment when you installed the telephone in your grand-parent's home. I have been through that one.

I can tell you a few tales. But I don't want to be philosophical about it. Maybe I am being philosophical. Do you think there has been any redeeming value in the experience that some of your younger ones have gone through by observing what you are living through.

Do you think that experience has been a favorable one, and as Congresswoman Boggs mentions the experience in England and sometimes the separation of families, the younger ones become alienated because of the care and attention being given to the older ones.

Have any of you found that sort of thing or do you feel that this experience is bringing the younger ones, adapting them better to the realities of life? Has it been a good experience or poor experience for them?

PREPARED STATEMENT OF HON. GEORGE C. WORTLEY A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW YORK

Mr. Chairman, I commend you for holding this hearing today. It is most timely as Congress considers child care and long-term care legislation.

I am in a unique position as I have the honor of serving on the Select Committee on Children, Youth, and Families and the Select Committee on Aging. While both committees have examined ways to bring relief to parents seeking adequate child care, and adult children caring for their elderly parents—little attention has been given to those adults who are truly "sandwiched-in." These people care for both the old and the young at the same time. We are long overdue in focussing attention on this special group.

Consider the following situation of one family in my district: A husband and wife in their sixties, retired with plans to travel during their "golden years" have the wife's 92-year-old mother and 98-year-old aunt living in their home. In addition are the couple's son, his wife and their two children. This couple is truly sandwiched-in by two seniors, two young adults and two grandchildren. The "golden years" for this couple means babysitting the grandchildren and frequent visits to the doctor for the elderly relatives.

This couple is absolutely remarkable in their stamina and ability to keep up with the needs of their family. But like others, they need a break! Senior adult day care is difficult to find for fragile seniors and quality child care is costly. The problem could be further exacerbated if the couple was still working. It would be almost unaffordable to hire outside care on a daily basis.

Where can this couple turn for relief? I look forward to hearing from the witnesses today. Each witness is an expert—either from a professional education or hands-on experience. This should be a most informative hearing.

Mr. McEUEN. I will comment on my 7-year-old son. He has had the double whammy. He has become deposed royalty because he has a brother five months old getting attention, and he has been watching me leave on Saturday or Sunday for a good part of the day to spend time with my mother in the nursing home.

I think he is resentful. He has come to think of my mother, his grandmother as a selfish individual. Certainly she is selfish, but she is also ill. Some of these demands are real demands. I try to meet them because I love her and because I try to maintain what dignity she has left. I did overhear him talking to one of his friends and he said, "You know, grandma is an alien." It is a great title for a song, but I don't know all that he means by that.

I think there is an important word. He feels alienated. I try to make him learn from this as any father would. I try to tell him that we all have limitations and that things aren't like they are in the Saturday morning cartoons.

Mr. WORTLEY. Some day father will be in the same situation as grandmother.

Mr. McEUEN. I am here out of my own enlightened self-interest, too. We are the baby-boom generation and when we age and we hit that health care system, it is going to shred if things aren't done to improve it. Yes, I found some resentment. It is manageable so far.

Mr. WORTLEY. Anybody else found resentment?

Ms. ARLEEN WARNOCK. I think more so than the younger child who wasn't even two yet, when he had to share his mother. A little bit with the teenagers, but as I said, I think they have learned from it. By the same token, even the little one will say, "Oh, Mom, do we have to visit Papa today?" That night if he is doing drawing or whatever, I will say, "That is nice." He'll say, "I think I will give it to Papa." It is two-fold there.

He knows that I have an obligation and he resents it whenever he would be out playing ball in the park. Then I think he knows the love that is involved there. So it is sort of two-sided.

Ms. LANE. I haven't run across this situation. I brought two babies home at one time—my father and my son. And my son literally fought tooth and nail the day my father died. He was 2 years old, but he felt the loss that intensely. That was a big part of his life. The situation when we tell our children, "do as I say, not as I do," in this situation they do as you do.

They see the love and caring from their parents going that direction and inadvertently time is short. It always is, but children learn to share and it comes back. You are teaching your children, in a sense, what you would like for them to be able to do in your situation, if you reach that point. I haven't run across that, not at all.

Ms. BRADY. I haven't either. My family has pulled together. I found that we have pulled together. We are a family. We love each other dearly. We have always spent a great deal of time together. And our plans, our future plans, as I had explained, were to keep the family together. I see where my 92-year-old grandmother is giving my 3-year-old a severely impaired child, as much love as she could possibly give him and he in turn has blossomed for her.

So I believe in the family, and as this lady said, you learn what your family teaches you and my family has taught me that the family is a very strong unit and you try to stay together, you stick together as much as you can.

Mr. WORTLEY. You are very wonderful people. God bless you and thank you for your efforts.

Chairman MILLER. Let me ask you a question. What do you pay for home health providers?

Ms. BRADY. It is going through third party health insurance at this point. If you try to hire people on your own, it is extraordinarily difficult, first of all, and second of all, the expense is astronomical.

Chairman MILLER. Such as?

Ms. BRADY. If you go for a nurse, an R.N., to work in your home, in my neck of the woods, if you go the agency route, it is $32 an hour. The agency gets half of that. If you hire a nurse on your own, the nurse gets $18 an hour. It is my understanding that recently that amount has gone up to $21 an hour for a licensed professional to work in your home.

There has got to be something in the middle, something has to be in the middle.

Chairman MILLER. So, on the basis on which you need it, it is not available?

Ms. BRADY. At present through third party health insurance.

Chairman MILLER. Will that continue for some period of time or——

Ms. BRADY. No, it is not. We are almost exhausted.

Chairman MILLER. What would happen then?

Ms. BRADY. Then we would have to turn to the medicaid system for Mathew. What that means, with the medicaid system, my understanding is that parental income has to stay within certain guidelines in order for Mathew to get that medicaid, his health coverage, all of his health expenses covered. I don't know what we are going to do. We have explored it with DSS, and we have spoken, and SKIP has been very wonderful in trying to help us. SKIP can help us——

Chairman MILLER. SKIP is the organization.

Ms. BRADY. Margaret Mikoll is the person who has been helping my family more so. She really understands.

Chairman MILLER. So your family has to become poorer, you think.

Ms. BRADY. Yes. Yes.

Chairman MILLER. You don't know to what extent, though?

Ms. BRADY. I don't know what the amount of money is that a family of three is allowed to earn within those guidelines.

Chairman MILLER. It is an all or nothing proposition, as you understand it.

Ms. BRADY. This is true.

Chairman MILLER. I am not that familiar with the entire thing.

Ms. BRADY. Yes. I institutionalize my son in order for him to get what he needs because I—or I keep him home and go for broke. That is probably what we are going to do because we can't see institutionalizing him. He needs to be with his family. It has done him a world of good.

Chairman MILLER. So you don't know the means by which, if any, he would be eligible for home health care?

Ms. BRADY. Only through the medicaid system.

Chairman MILLER. Provided you give up some income or assets or whatever.

Ms. BRADY. We have given up a lot.

Chairman MILLER. I understand that, but apparently what you are saying is, I will have to check this out, you will be required to give up even more income or assets and there is not even a sliding scale.

Ms. BRADY. I can't see how I would be able to pay for our mortgage and all the things that people usually pay for in life and still remain within guidelines so that you can live a relatively normal life but also be able to maintain your child at home.

Chairman MILLER. Debbie, in terms of your personal experiences, I understand you may have had some problems at school in terms of people understanding what you were going through.

Is that accurate?

Ms. DEBBIE WARNOCK. I go to Catholic school. I always thought that a Catholic school was supposed to care more than a public school. Everybody was supposed to care and love everything.

When I was a freshman, my mother did not live at home. She lived with my grandfather. My guidance counselor said to me, "I forgot, your mother doesn't live with you, she doesn't care about you."

Chairman MILLER. She was living with your grandfather, who was ill?

Ms. DEBBIE WARNOCK. Yes.

She said that to me, and I had thought it was a great school. I was shocked she would say something like that.

How could you say your mother doesn't care about you because she doesn't live with you, when she is needed somewhere else?

Chairman MILLER. Mr. Holloway.

Mr. HOLLOWAY. I have no questions. Thank you.

Chairman MILLER. Thank you very much for your testimony and for sharing this with the committee.

Over the next month or so, the Congress is going to be debating two huge issues. One is catastrophic health care and the other is long-term health care, both for children and the elderly. I expect that certainly the long-term health care debate will probably move the health care issue further along in this country than it has been in the last 20 years.

I think there is growing recognition in the Congress—maybe it is because there is a growing number of baby boomers—of the sandwich generation, where we are looking through both ends of the telescope. It is putting pressure on our constituents. Without destroying the strength you have shown in terms of maintaining your families, we must also be sure we don't destroy the families by overburdening you with stress which is way beyond your caring capacity, and the capacity of the rest of the members of your family.

You may want to watch those debates. I think they are going to be politically very significant in terms of this whole health care and caregiving debate over the next couple of years. This is the starting point, if you will, in terms of what I think will be a roaring national debate, as families confront the inadequacies of the current situation, as we find fewer and fewer people who are in a position to subsidize the care of the family because they must work, and meet other responsibilities.

Thank you. I think you really have been very, very helpful. I appreciate your time and what you are doing. Thank you very, very much.

The next panel the committee will hear from will be composed of Susan Kornblatt, a member of the Board of Directors of Family Survival Project, and a gerontologist at the University of California at San Francisco; Dr. Kenneth G. Johnson, Director of the National Interfaith Volunteer Caregivers Program, and Adjunct Professor of Community Medicine at the Mount Sinai School of Medicine; Elaine M. Brody, Associate Director of Research at the Philadelphia Geriatric Center; J. Knox Singleton, Chairman of the Volunteer Development Committee, Fairfax County Commission on Aging; Dorothy Frances, Friendly Visitor, Retiree Service Department, International Ladies' Garment Workers Union in New York; and Al Nestor, Director of the Franconia Family Therapy Center in Alexandria.

STATEMENT OF SUSAN KORNBLATT, MEMBER, BOARD OF DIRECTORS, FAMILY SURVIVAL PROJECT, AND GERONTOLOGIST, UNIVERSITY OF CALIFORNIA, SAN FRANCISCO, CA

Ms. **Kornblatt**. I am Susan Kornblatt. I am a member of the Board of Directors of the Family Survival Project, FSP, headquartered in San Francisco, California. Professionally I am a gerontologist at the University of California, San Francisco.

I am particularly delighted to be here today because Chairman Miller is one of our members from the San Francisco Bay area, one whom we love and respect.

I joined the Family Survival Project board a year ago as a consumer member. My stepfather has both Alzheimer's and Parkinson's diseases. My mother works full-time. Although I do not have children, both of my siblings do. As a result, all of the burden of care for my stepfather has fallen on my mother and myself.

Across the United States millions of adults each year fall victim to brain damage from an array of illnesses and conditions, such as Alzheimer's disease, stroke, head injury, Parkinson's and Huntington's diseases, loss of oxygen and brain tumors. And each year the families of these victims are faced with the heavy task of caring for loved ones who can no longer care for themselves.

For some it means juggling work, caregiving and other family responsibilities. For others it means quitting a job to give care. For still others it means contemplating help from a service agency for the first time.

Individuals with dementing disorders are among the most difficult to care for. Personality changes, bizarre behaviors and the years of constant care required hit hard on the family. Caregivers frequently carry the burden alone and come to a service agency only after great pain and hardship.

As one adult daughter, caring for her mother, an Alzheimer's victim, described her situation, "The steps of watching an Alzheimer's patient slowly deteriorate—a brilliant professional woman who can no longer walk, talk or do most things to help herself—are very painful. You think you are coping and then you have a heart attack. I had a coronary three years ago from stress."

Family Survival Project was founded over a decade ago by a task force of citizens alarmed at the San Francisco Bay area's lack of resources for brain-impaired adults and their families. The task force was formed in response to a San Francisco woman who could find no help for her husband, a victim of Alzheimer's disease.

When FSP was established, there was no other organization in the country to address the problems of brain-impaired adults and, equally important, those of their families. Since 1976, therefore, we have operated on two levels: one, to provide direct services and program development in the greater San Francisco Bay area; and, two, to conduct public awareness and social policy development wherever such attention is needed.

After developing model legislation and pilot programs, the founders incorporated FSP in 1980 as a nonprofit community agency designed to meet the most basic and frequently cited needs of family caregivers, including general information, respite from caregiving, emotional support, legal and financial information and advice, and direct care of the patient.

In 1984 landmark legislation—Chapter 1658, 1984 Statutes—was passed in California to establish a statewide system of Regional Resource Centers modeled after FSP's innovative service model, which I will describe shortly. Seven resource centers currently exist in the state and four more will begin operation in June 1988.

With the passage of this law, FSP also undertook a new role: to serve as the statewide resources consultant to the State of California to help plan and set up new resource centers; to conduct training, education and social policy research; to operate a statewide clearinghouse on brain disorders and caregiving; and to develop a coordinated response to the needs of this population.

This law made California the first state in the nation to act upon the severe inadequacy of assistance and long-term care for this neglected population. Equally important, the law addressed a new significant client: the family or caregiver responsible for the often 24-hour needs of a brain-impaired adult.

Each year FSP serves over 2,500 new families and caregivers. Most—75 percent—are female, between the ages of 36 to 64—56 percent. One-third are adult daughters caring for an elderly parent. Many of them also have children at home—"women in the middle." About one in three are working caregivers, juggling careers, caregiving responsibilities and other family demands.

One 42-year-old woman caring for her father, a dementia victim, described her situation plainly, "I find my health suffered, and my nerves. It's a very difficult job caring for a loved one, knowing they will never get better."

What services do families need?

The number one need is for basic information to link the caregiver with needed services. More often than not, the average family is unaware of services available in the community and how to access them. Families need information on how and where to get help, what the implications of a diagnosis are, and costs and burdens they are likely to face. Resource information is needed not only at diagnosis, but throughout the oftentimes long years of caregiving.

Families need emotional support. Family support services are of vital help. Services include planning and problem solving, counseling and support groups.

Caregivers need relief. Studies show it doesn't have to be much, but it should be periodic, easy to obtain and continual. It should be available all through the caregiving process, not just at the last second when the patient is in dire need or the caregiver is near exhaustion. Respite care specifically addresses the needs of the caregiver. Respite, or temporary relief away from the caregiving role, is a crucial service to ease the burden of constant care. Respite can be provided in the home, in an adult daycare setting, by temporary placement of the patient in a facility for a weekend, or a combination of these options.

The respite program at FSP and California's other regional resource centers has been cost effective both in terms of helping families and in providing a lower cost alternative to institutional placement. In 1987 the average monthly state cost per family client was $221. Three out of four families contributed to the cost of respite care. On the average, caregivers received nine hours of respite per week.

Services should also be developed to conserve family resources. Early intervention is crucial to avoid having a family exhaust all its resources to provide long-term care. Legal and financial information and advice should be provided by knowledgeable attorneys to help families plan for long-term care and resolve complex legal issues. FSP contracts with attorneys to provide one hour of free legal consultation to help family caregivers.

The last major service component is training and education. Families need information about how to give care, to develop skills in managing unfamiliar behaviors and to learn more about the long-term effects of brain disorders.

We have learned that together these services prolong the family's ability to care at home for their relative. By providing needed information and support, families are given the means to make informed decisions about continued care. Without such assistance, families soon become isolated, depressed, impoverished, and in some instances physically ill, leaving two patients instead of one.

In 1986 FSP decided to take a closer look at our family clients who are both caregivers and employed outside the home. A summary of all the findings has been given to the committee members. I would like to highlight some striking points.

These caregivers spend as much time at work as they do providing care—35 hours average on the job and another 35 hours average providing care. Three-fourths are women, and typically they are adult daughters or daughters-in-law, many with children at home. 22 percent of those who are not employed had quit their jobs to give care.

As Chairman Miller previously pointed out, they estimated their lost income as over $20,000 a year. They have spent an average of 18 hours a day giving care, which is obviously more than most people spend on a job.

One of the 49-year-old daughters in the study described her life after quitting her job to care for her parents, one with Parkinson's and another with a stroke, "The past couple of years I have been essentially full-time at providing and supervising their care. It is lonely and devastating to watch the total deterioration of my parents."

Many adult daughters who quit their jobs want to return to work—two-thirds.

One 42-year-old woman working and caring for her mother said, "If I did not have a flexible job, I would be fired by now. Between my kids trying to get attention and my mom's needs, I feel like a nervous breakdown waiting to happen."

In conclusion, we need to develop a long-term care policy at state and national levels which incorporates support for the families. We must see families as part of the patient treatment unit, to develop policies and programs for family-based services.

Over a decade ago the public was generally unaware of long-term consequences of the onset of brain damage. The California law is making significant progress in helping families with the enormous burdens that many of us face.

We stand by and are ready to work with you in developing and extending the family service model.

Thank you.

Chairman MILLER. Thank you.

[Prepared statement of Susan Kornblatt follows:]

PREPARED STATEMENT OF SUSAN KORNBLATT, MEMBER OF THE BOARD OF DIRECTORS OF THE FAMILY SURVIVAL PROJECT (FSP), SAN FRANCISCO, CA

Chairman Miller, Committee members and other interested persons here today. My name is Susan Kornblatt. I am a member of the Board of Directors of the Family Survival Project (FSP), headquartered in San Francisco, California. Professionally, I am a gerontologist at the University of California, San Francisco.

I joined Family Survival Project's Board one year ago as a consumer member. My stepfather has both Alzheimer's and Parkinson's diseases. My mother works full-time. Although I do not have children, both my siblings do. As a result, all of the burden of care for my stepfather has fallen on my mother and myself.

Extent of the problem of Adult-Onset Brain Damage

Across the United States millions of adults each year fall victim to brain damage from an array of illnesses and conditions such as Alzheimer's disease, stroke, head injury, Parkinson's and Huntington's diseases, loss of oxygen, and brain tumors. And each year, the families of these victims are faced with the heavy task of caring for loved ones who can no longer care for themselves.

For some, it means juggling work, caregiving and other family responsibilities. For others, it means quitting a job to give care. For still others, it means contemplating help from a service agency for the first time.

Individuals with dementing disorders are among the most difficult to care for. Personality changes; bizarre behaviors, and the years of constant care required hit hard on the family. Caregivers frequently carry the burden alone coming to a service agency only after great pain and hardship. As one adult daughter, caring for her mother, an Alzheimer's victim, described her situation:

> "The steps of watching an Alzheimer's patient slowly deteriorate — a brilliant professional woman who can no longer walk, talk or do most things to help herself, are very painful. You think you are "coping" and then you have a heart attack...I had a coronary three years ago from stress."

History and Background of Family Survival Project

Family Survival Project (FSP) was founded over a decade ago by a task force of citizens alarmed at the San Francisco Bay Area's lack of resources for brain-impaired adults and their families. The task force was formed in response to a San

Francisco woman who could find no help for her husband, a victim of Alzheimer's disease.

When FSP was established, there was no other organization in the country to address the problems of brain-impaired adults, and equally important, those of their families. Since 1976, therefore, we have operated on two levels: one, to provide direct services and program development in the greater San Francisco Bay Area; and two, to conduct public awareness and social policy development wherever such attention is needed.

After developing model legislation and pilot programs, the founders incorporated FSP in 1980 as a non-profit, community agency designed to meet the most basic and frequently cited needs of family caregivers, including: 1) general information; 2) respite from caregiving; 3) emotional support; 4) legal and financial information and advice; and 5) direct care of the patient.

In 1984, landmark legislation (Chapter 1658, 1984 Statutes) was passed in California to establish a statewide system of Regional Resource Centers modeled after FSP's innovative service model which I will describe shortly. Seven resource centers currently exist in the state; four more will begin operation in June, 1988. With the passage of this law, FSP also undertook a new role: to serve as the "Statewide Resources Consultant" to the State of California to help plan and set up new resource centers; conduct training, education and social policy research; operate a statewide clearinghouse on brain disorders and caregiving; and develop a coordinated response to the needs of this population.

This law made California the first state in the nation to act upon the severe inadequacy of assistance and long-term care for this neglected population. Equally important, the law addressed a new significant client: the family or caregiver responsible for the often 24-hour needs of a brain-impaired adult.

Each year, FSP serves over 2,500 new families and caregivers. Most (75%) are female, between the ages of 36 to 64 (56%). One-third are adult daughters caring for an elderly parent. Many of them also have children at home -- "women in the middle".

About one in three are working caregivers, juggling careers, caregiving responsibilities and other family demands. One 42-year-old woman caring for her father, a dementia victim, described her situation plainly: "I find my health suffering and my nerves. It's a very difficult job caring for a loved one, knowing they'll never get better".

What services do families need?

The Number One need is for basic Information to link the caregiver with needed services. More often than not, the average family is unaware of services available in the community and how to access them. Families need information on: how and where to get help, what the implications of a diagnosis are, and costs and burdens they are likely to face. Resource information is needed not only at diagnosis, but throughout the often times long years of caregiving.

Families need emotional support. Family support services are of vital help. Services include planning and problem-solving, counseling, and support groups.

Caregivers need relief. Studies show it doesn't have to be much, but it should be periodic, easy to obtain, and continual. It should be available all through the caregiving process, not just at the last second when the patient is in dire need or the caregiver is near exhaustion. Respite care specifically addresses the needs of the caregiver. Respite — or temporary relief away from the caregiving role — is a crucial service to ease the burden of constant care. Respite can be provided in the home, in an adult day care setting, by temporary placement of the patient in a facility for a weekend, or a combination of these options.

The respite program at FSP and California's other regional resource centers has been cost-effective both in terms of helping families and in providing a lower cost alternative to institutional placement. In 1987, the average monthly state cost per family client was $221. Three out of four families contributed to the cost of respite care. On average, caregivers received nine hours of respite per week.

Services should also be developed to conserve family resources. Early intervention is crucial to avoid having a family exhaust all its resources to provide long-term care. Legal and financial information and advice should be provided by knowledgeable attorneys to help families plan for long-term care and resolve complex legal issues. FSP contracts with attorneys to provide one hour of free legal consultation to help family caregivers.

The last major service component is training and education. Families need information about how to give care, to develop skills in managing unfamiliar behaviors, and to learn more about the long term effects of brain disorders.

We have learned that, together, these services prolong the family's ability to care at home for their relative. By providing needed information and support, families are given the means to make informed decisions about continued care. Without such assistance, families soon become isolated, depressed, impoverished, and in some instances, physically ill, leaving two patients instead of one.

The needs of working caregivers

In 1986, FSP decided to take a closer look at our family clients who are both caregivers and employed outside the home. Two trends: the dramatic growth in the oldest segment of the population, those most likely to suffer a brain impairment such as Alzheimer's disease or stroke, and the influx of women into the labor force are beginning to take their toll. Women are less available as traditional unpaid caregivers. As these trends continue the need for caregivers will grow and more caregivers will also be workers.

With the help of the Fellowship Program of the Gerontological Society of America, funded by the Administration on Aging, FSP conducted a study of 284 Bay Area caregivers. In the interest of brevity a summary of the study findings has been given to Committee members, and additional information can be provided upon request. I would, however like to highlight some of the more striking findings. Working caregivers of brain-impaired adults spend as much time at work as they do providing care, that is an average of 34 hours/week on the job; and 35 hours/week providing care. Nearly three-fourths of working caregivers are women, typically the adult daughters and daughters-in-law of the patient. One in four also have at least one child at home.

Twenty-two percent of the not employed caregivers quit their jobs to give care. They estimated their lost income to be $20,400 a year. And they spend an average of 18 hours a day giving care, considerably more time than they would spend working at a job. One 49-year-old daughter in the study described her life after quitting to care for both her parents, one a victim of Parkinson's disease, the other of stroke:

> "The past couple of years I have been essentially full-time at providing and supervising their care...It is lonely and devastating to watch the total deterioration of my parents."

Two-thirds of the adult daughters who did quit wanted to return to work. A 42-year-old woman caring for her mother summed it up succinctly:

> "If I didn't have a flexible job, I'd be fired by now. Between my kids trying to get attention and my mom's needs, I feel like a nervous breakdown waiting to happen".

Conclusion

We clearly need to develop a long-term care policy, at both the state and national levels, which incorporates support for the family. We must see families as part of the patient treatment unit and develop policies and programs for family-based services.

Changing demographics are causing more and more families to be touched by dementing illnesses and other disorders which require long-term care. More and more, caregiving problems are directly affecting each one of us. It has become a personal issue. And a personal issue will drive us to act.

Over a decade ago, when FSP was formed, the public was generally unaware of the long-term consequences of adult-onset brain damage. California's landmark law is making significant progress in helping families deal with the enormous burdens they face as caregivers. We stand ready to work with you to extend this service model.

On behalf of the Board of Directors of Family Survival Project I thank you for the honor and privilege of testifying before you today.

A RESEARCH SUMMARY FROM FAMILY SURVIVAL PROJECT

OVERWORKED, UNDERESTIMATED THE EMPLOYED CAREGIVER DOING DOUBLE DUTY

Wednesday, 5 p.m.

Barbara's heading home from work after a tough day. At 6 a.m. she was making breakfast, beds, lists for Evelyn. Finding homework, socks, car keys before Evelyn arrived at 8. With a goodbye kiss for her mother-in-law, she'd driven her boys to junior high and made it to work by 9. She'd wanted to stay late to help her boss meet a big deadline. But she couldn't. She has to be home by 5:30 when the kids leave for the softball game. Her husband Jim is out of town, Evelyn left when the boys got home from school and Jim's mother can't be left alone. She's likely to wander off or leave the stove on. Jim's mother has Alzheimer's disease. Barbara is her primary caregiver. Evelyn is a home care aide.

Each year the Family Survival Project for Brain-Damaged Adults in San Francisco helps thousands of family caregivers. A growing number (now 1 in 3) are like Barbara -- juggling caregiving for a brain-impaired relative with other family demands and employment. Barbara is relatively "lucky" for her family can afford to hire help during the work day and she has not had to quit her job.

As the population ages, the incidence of brain damage in adults is increasing. It is estimated that one family in four will be touched by this problem. Onset may be slow, as with Alzheimer's disease and other related dementias in which confusion and memory loss precede total decline of mental functioning and eventual loss of physical health. Or brain damage can occur suddenly, with an injury, infection, stroke or loss of oxygen. Brain-impaired patients often (or eventually) need years of 24-hour care or supervision. Caregiving may entail managing the patient's difficult behavior and changed personality. One woman served by the Family Survival Project has cared for her 50-year-old daughter more than 30 years -- since an automobile accident left her brain-damaged, unable to feed or dress herself or be on her own more than briefly.

The Family Survival Project's services and activities support caregivers who themselves become victims of the physical, emotional and financial consequences of brain damage. Most often these caregivers are middle-aged or older women caring at home for an older male disabled by a dementing illness or a stroke. But clients range in age from 18 up and their relatives' disorders stem from all sorts of causes, including accidental head injury, brain tumor and Parkinson's disease.

The Family Survival Project has taken a close look at the impact on its clients of the dual role of caregiving and employment. Two demographic trends underscore the urgency of this issue for the agency's clientele and for the nation. The first -- increasing longevity -- reveals an absolute and proportional growth in the oldest segment of the population, those 85 and older. This group is most likely to suffer brain impairment from causes such as Alzheimer's disease and stroke. Second, the dramatic influx of women into the labor force reduces the availability of the traditional unpaid caregiver. Putting the two together suggests that **the need for caregiving will grow and more caregivers will also be workers.** Pressures on both caregivers and the workplace are sure to mount.

With the help of the Fellowship Program in Applied Gerontology of the Gerontological Society of America, the Family Survival Project conducted a study of employed caregivers in the Summer of 1986. Under the direction of Robert Enright, Jr., Ph.D., of the University of Wisconsin at Steven's Point, the study was designed to answer such questions as: Who are the employed caregivers of brain-impaired adults? How do employed caregivers differ from those who do not hold jobs? What is the social and psychological impact of giving care and working outside the home? What is the impact of caregiving on employment?

The Study's Focus

The Family Survival Project's study focuses on 284 primary caregivers in the San Francisco Bay Area: 143 employed, 141 not. "Primary caregivers" have the greatest responsibility for care but are not paid to provide that care; an "employed" caregiver has a paying job outside the home. The study looks first at the group as a whole (all 284), then at the differences and similarities between employed and not-employed caregivers.

Study participants are all clients of the Family Survival Project, chosen by the following process: (1) all Bay Area clients (more than 3,000 families) were sent a brief pre-survey; (2) all employed primary caregivers and an equal number of not-employed returning the pre-survey were sent a 50-item questionnaire; (3) those who returned these questionnaires made up the sample of 284.

Who Are The Caregivers?

The 284 primary caregivers are much like the Family Survival Project's total client population: predominantly middle-aged, middle-income women, living alone with their brain-impaired relative.

- Their average age is 59, yet some are as young as 22 and others as old as 87.
- Their median household income (1986) is $31,136; their personal income $15,000.
- They are mainly wives (35%), daughters (22%) and mothers (10%) of the patients, but some are husbands (19%), sisters, brothers, grandchildren, aunts, more distant relatives and friends.
- More than three-fifths (62%) live with the patient. Most (57%) have no other adult in the household.

Caregiving is hard on them and they don't receive much help.

- Most (61%) are caring for relatives with dementia.
- Their patients range in age from 18 to 93, with the average, 67. Many wander (48%), cannot be left alone (78%), awaken the caregiver at night (77%) and are stubborn or combative (84%). Two-thirds need help to bathe or take medications, three-fifths cannot dress themselves, half cannot go to the bathroom alone and one-third need help to eat.
- They have been providing care an average of five years, 59 hours a week, with 28 hours paid help and less than two hours help from other kin outside the patient's household.
- Many frequently feel tired (59%), are usually tense or anxious (42%) and feel quite burdened (46%).
- One-fifth have not had a vacation in five years.

> ***"I find my health suffering and my nerves,"*** *says a 42-year-old daughter caring for her father who has dementia.* ***"It's a very difficult job caring for a loved one, knowing they'll never get better . . ."***

How Do Employed Caregivers Differ From The Not-Employed?

While the two groups of caregivers have much in common, for example, three-fourths of each group are women and most (89%) are white, there are many differences. Compared to the not-employed caregiver, the employed is younger, more affluent, slightly better educated, more likely to be unmarried and less likely to be living with the patient.

- Their average age is 52, versus 65 for the not-employed.
- Their median family income is $39,500, much higher than the not-employed's $23,700.
- They have one more year of education (15 versus 14 years).
- Three times as many are divorced or separated (12% versus 4%) or never-married (13% versus 4%).
- The employed tend to be adult daughters and sons of the patient; the not-employed, wives or husbands.
- They are much more likely to place their relative in a nursing home or other care facility (39% versus 23%). Half live with their brain-impaired relative, versus three-fourths of caregivers without jobs.
- The employed have, on the average, 16 hours per week more help (36 versus 20 hours).

Although employed caregivers are an average of twelve years younger than the not-employed, they have been providing care nearly as long (4.4 versus 5.8 years). The employed are twice as likely to care for a victim of head injury (19% versus 10%). For both groups, most are caring for an adult with Alzheimer's disease or other form of dementia. Those in the workplace tend to care for a female relative; the not-employed tend to care for a male.

There is also a great diversity among employed caregivers. Half are professionals and managers, one-fourth are clerical workers and the remainder sales employees (15%) and crafts or service workers (11%). Nearly half work part-time, with one-sixth working more than 40 hours weekly and one-third working a full-time 40-hour week. Their average work week is 34 hours.

Each week the average employed caregiver spends more time giving care (35 hours) than at her job. If the patient is in the caregiver's home, much more time is involved: these employed caregivers give more than 47 hours of care weekly.

What Is The Impact Of Caregiving On The Employee?

An employee responsible for providing care to a brain-impaired relative can react in a variety of ways depending upon the patient's needs and residence, the amount of support received from family and friends, and the amount of income available to hire help. Most (72%) say working makes caring for their relative easier.

> *"Working gives me an outlet," says the 57-year-old wife of an Alzheimer's victim. "I'm more patient because I've had time away. Working is satisfaction and my co-workers are very supportive."*

The caregivers who fare the best continue to work more than 40 hours a week and can afford substantial in-home help, adult day care, or nursing home care for their relatives. On the other hand, an employed caregiver who must work to make ends meet has a very stressful predicament. A caregiver with a severely impaired patient in the home loses time at work, decreases the hours worked or quits if adequate outside help cannot be afforded.

- More than half those employed half-time or more report missing time at work due to caregiving responsibilities. They miss an average of more than a day a month (9.3 hours).
- Nearly three-fifths of all those employed report sometimes working slowly due to their caregiving concerns.
- Over half employed 20 hours or fewer say caregiving caused them to reduce their hours.
- One-fifth (22%) of the not-employed have quit their jobs to provide care full-time. If they live with the patient, they now spend an average of *123* hours per week in caregiving (17.5 hours a day).

The study reveals this profile of the 9-5er who is the backbone of American enterprise: She holds on to her 40-hour-a-week job as long as she can because her family depends on the income. As the patient's condition worsens, she loses time from work and increases her level of stress as competing demands take their toll. Eventually she has to reduce her hours and her salary. She does not quit until she has to, but may have to change jobs.

> *"I left teaching to take a job with flexible hours, but also sacrificed salary,"*

Explains the 59-year-old caregiver wife of a man who had a stroke. If her relative then requires continuous care, she must quit for her family cannot afford to pay for adequate help. She then spends all her waking hours as a caregiver.

Not surprisingly, caregivers who quit or reduce their hours drastically have the highest levels of stress. They also have relatives with the most severe behavioral problems (awakening them at night, wandering, requiring constant supervision). When they quit, their annual income loss is about $20,400 each (1986) and they lose much more. A 53-year-old woman caring for her husband with Alzheimer's disease sums it up:

> *"It is not easy; I sure would like to go back to work. Some days it drives me nuts to stay at home. I don't get enough exercise and get tired doing things... Somehow I lost my friends..."*

What Can Employers Do?

Often the employees trying to cope with caring for a severely disabled relative are good, seasoned workers who have given years of service to their employers. They may be senior managers or twenty-year bookkeepers. The problem cuts across all job classifications. What should be done to help these workers?

First and foremost, **recognize that the problem exists in almost every workplace.** Businesses are now beginning to survey their employees to find out how many are caregivers and what their needs are. They are finding that as many as one in five of their employees over 30 years of age is caring for an older relative. And that employees need help but are reluctant to share such a "personal" issue with supervisors, even if their work suffers. So, look around: that employee who is using the telephone excessively at work and has increasing tardiness, unscheduled days off or absenteeism may be a caregiver who needs support and understanding.

Second, **periodically and conveniently provide information about community resources** that can assist caregivers: home care, adult day care, legal advice, support groups, financial assistance, aid in finding appropriate nursing homes or other residential care facilities. Family Survival Project finds that caregivers' greatest need is for information -- about the causes of brain damage, the methods of treatment and the resources that can be tapped for care. An annual "caregiver fair" can feature such information where the caregiver works.

Third, **work together with community organizations.** An increasing number of health and social service agencies are offering planning assistance for long term care in and out of the home, and other family support services such as respite care, counseling, and training programs. Family Survival Project and six other regional resource centers in California offer many of these services for family caregivers and can extend the services to employer-referred families.

Fourth, if it is possible, **enable the caregiving employee to adjust his or her work schedule.** Family Survival Project's study shows that caregivers want to keep working and that those who work more than half-time but less than full-time are less stressed. Achieving a balance between work and caregiving responsibilities is crucial to the well-being of the caregiver, the family and the firm that wants to retain valuable employees.

Finally, maintaining an adequate family income is key to coping with the dual work-caregiving role. Therefore employers need to **consider shifts in benefit plans** to help the increasing number of employee-caregivers purchase home care, adult day care and nursing home care, and to allow them to earn extended, paid caregiving leave.

How Can Family Survival Project Be Of Help?

Technical assistance is available to companies from Family Survival Project. Founded 11 years ago, Family Survival Project was the first community organization in the country created to assist families and caregivers of adults suffering from Alzheimer's disease and other brain disorders that are acquired in adult years. The organization has twice sponsored successful legislation in California to establish new programs for brain-impaired adults and their families. Numerous other organizations have been helped by the Family Survival Project to develop services.

Today, Family Survival Project operates a six-county regional resource center in the San Francisco Bay Area providing information and referral, family support services such as counseling and respite care, community education and technical assistance, and as the State of California's Statewide Resources Consultant on brain impairments and caregiver assistance, Family Survival Project operates an information clearinghouse and is helping to implement a statewide system of services.

Family
Survival
Project

Resource Center for families
of brain-damaged adults.

For more information about the
Employed Caregiver Study and services, contact
Family Survival Project, 44 Page Street, Suite 600,
San Francisco, CA 94102, (415) 626-6556 or in
California, toll-free (800) 445-8106.

FAMILY SURVIVAL PROJECT

ANNUAL REPORT
OF THE STATEWIDE RESOURCES CONSULTANT

PROGRAMS FOR BRAIN-IMPAIRED ADULTS AND THEIR FAMILIES
1987

EXECUTIVE SUMMARY

The enactment of Chapter 1658 in 1984 established statewide and regionally-based services for families and caregivers of adults stricken with brain impairment after age 18. This landmark law made California the first state in the nation to act upon the severe inadequacy of assistance and long-term care for victims of progressive or irreversible brain damage or disease. Equally important, the law addresses a new significant client: the family or related caregiver who must take responsibility for the often 24-hour needs of brain-impaired adults.

The population addressed are those adults who manifest a permanent, significant destruction of brain tissue with resultant loss of brain function after the age of 18. These disorders include those which cause dementia, such as Alzheimer's or multi-infarct disease; degenerative diseases which cause both physical and cognitive impairment, such as epilepsy, multiple sclerosis, Parkinson's and hereditary diseases such as Huntington's; cerebrovasular disease such as strokes, or aneurysm; brain injury as a result of trauma, anoxia, infection and other illnesses; and brain damage from temporary or progressive conditions, including tumors, hydrocephalus, and abcesses. Chapter 1658 recognizes that all forms of brain damage cause similar problems, no matter a persons's age, sex, race, occupation or economic status. Programs must also address the physical, emotional and financial impact on families and caregivers that results from changes in the patient's personality, behavior and ability to perform daily activities.

In California the needs of brain-impaired adults and their families were first brought to the attention of the Legislature and health and welfare agencies by a voluntary task force and its state-funded needs assessment study. Now known as the Family Survival Project (FSP), the group demonstrated that brain-impaired Americans literally fell through the cracks of health, mental health, social service and legal systems, primarily as a result of the diagnostic categories and other eligibility criteria upon which those systems are based. In subsequent years, the FSP operated a pilot project, established by legislation in 1979, to develop model services and policies.

Chapter 1658 (California Statutes of 1984) was signed into law on September 30, 1984. The law directs the Department of Mental Health (DMH) to establish, within four years, "Regional Resource Centers" (RRCs) throughout the state. These centers are to make possible a single-entry information network within each RRC service region as well as the provision and development of appropriate programs and services for brain-impaired adults and their caregivers. At the end of 1987, seven centers were in operation.

In addition, Chapter 1658 established a "Statewide Resources Consultant" (SRC) to serve as the centralized information and technical assistance clearinghouse on brain impairment; to provide consultation, training and technical assistance to the RRCs, and to help evaluate their effectiveness; to conduct conferences and develop training programs; to conduct public social policy research; and to assist the State in coordinating Chapter 1658 and other state initiatives. The Family Survival Project was awarded the SRC contract commencing February 7, 1985.

As the SRC, Family Survival Project must prepare annual reports for the California Department of Mental Health and State Legislature on the progress of Chapter 1658 programs. This Executive Summary is for the third Annual Report prepared by the Statewide Resources Consultant in cooperation with the Department of Mental Health on the progress of Chapter 1658. Highlights of progress and activities include:

Statewide Resources Consultant (SRC)

During 1987 the SRC continued to collect, classify and analyze resource, policy and research materials available in the Statewide clearinghouse. Up-to-date information was disseminated regularly to more than 16,000 individuals and organizations through a variety of publications. The SRC responded to nearly 750 new contacts to the Statewide Clearinghouse, a 19 percent increase in the number of first-time information requests to the SRC over the previous year. The report summarizes the data collected from these contacts.

The first system for collecting uniform statewide data on family caregivers, and the brain-impaired adults they care for, served by Regional Resource Centers was refined and implementation began incrementally with existing RRCs. The SRC analyzed data reported by the seven RRCs on a quarterly basis for the Department of Mental Health. The SRC provided training and technical assistance to RRC staff, conducted technical assistance visits and developed policy and procedural materials. The SRC also organized the first educational conference for all RRC staff in June, 1987.

In addition, the SRC sponsored a Public Policy Forum to identify salient policy issues for brain-impaired adults and their caregivers. Participants from throughout the state identified three priority areas: respite care financing; long-term care insurance; and a comprehensive package of services for the traumatically brain-injured.

In social policy research, the SRC completed a pioneering study examining the dual role of caregiving and employment. The study results suggest that the need for caregivers will grow and more caregivers will also be workers. Pressures on both the caregiver and the workplace are sure to mount.

In the area of epidemiological research, the SRC conducted a review of the literature in an attempt to estimate the prevalence of the major causes of brain damage in the United States, in general, and California, in particular. The report details the results of this research.

SRC staff also worked with several state departments and federal agencies to coordinate developments in programs and services for brain-impaired adults and their families for professional training.

Regional Resource Centers (RRC)

The report provides an overview of RRC functions and highlights services provided and data collected at seven RRCs that were operational in 1987. The sites are:

- Bay Area Resource Center (Family Survival Project)
- Inland Counties Resource Center (San Bernardino Community Hospital)
- Los Angeles Resource Center (Harbor Developmental Disabilities Foundation)
- Redwood Empire Resource Center (Brain-Impaired Adults Resource Center, Catholic Charities of the Diocese of Santa Rosa)
- Del Oro Resource Center (Brain, Inc.)
- Southern Resource Center (Sharp Memorial Hospital)
- Coast Resource Center (Rehabilitation Institute at Santa Barbara)

A profile of the three newest RRCs (Del Oro, Southern and Coast) is presented describing each center's start-up, organization, community relations, education and training, resource development activities, and client services. Case histories of typical client families are included. Caregiver, patient, service and cost data collected are presented for all seven RRCs.

In total, the seven centers responded to 5,229 initial inquiries from family members and providers during 1987. Of those, two-thirds were family members and caregivers. More than three-quarters of these callers were women, and about one-third were elderly (over age 65). Differences among the regions are described. Of patients identified, 54 percent were male; the majority were elderly. Those at least 85 years of age account for 18 percent of the 65+ patient population, twice the national average. More than half of disorders were Alzheimer's disease or a related dementing illness. Over 80 percent of patients resided at home.

Preliminary results from the pilot test of the uniform client assessment tool show that one in three caregivers reported receiving no help at all for the care of their patients from either service providers or from other family members and/or friends. Caregivers averaged 15 problems indicating that the caregivers' resources are greatly strained. A significant proportion (70%) of family members reported being highly stressed by their caregiving situation. Most are at great risk of personal impoverishment due to the high cost of long-term care.

All family caregivers contacting RRCs received information and referral services. Four out of ten received one or more additional direct services including family consultation, counseling, legal information/advice, and/or support groups. Over 5,000 individuals attended an RRC sponsored training event. A total of 485 families received respite care. By the end of 1987, 357 families, however, in need of respite care remained on an RRC waiting list for these services.

Respite care services cost the State of California $514,485, with more than three out of four family clients contributing to the cost of service. The average respite expenditure per family per month was $237, of which the State spent $221.

Unmet Needs And Emerging Areas of Concern

The report summarizes service and resource needs documented by each RRC. This section shows the deficiencies in service availability for the target population and how availability differs from county to county. Overall, the need for basic, accurate, information remains high statewide. Two of the severest program needs are highlighted: the dearth of services for head-injured persons and the lack of respite care funding. Two emerging areas of concern are identified: the needs and problems of employed caregivers and the growing population suffering from AIDS dementia.

Conclusions and Recommendations:

The report offers several conclusions and recommendations that would further the goal of Chapter 1658 to establish a statewide comphrensive set of policies and programs for brain-impaired adults and their caregivers. The report recommends that:

- the existing geographic boundaries of the RRCs be examined;
- the RRCs' resources be expanded to meet the demand for affordable and accessible respite care;
- the SRC's resources be expanded commensurate with the number of operational RRCs;
- the resources of the Statewide Clearinghouse be expanded to keep pace with demand and information development;
- a comphrensive legislative initiative for adult with traumatic brain injury be developed that would, at a minimum, address:
  1) coordination for the head-injured across State agencies;
  2) designation of license criteria;
  3) development of adult education/jobtraining through the state community college system; and
  4) compilation of a statewide resources directory;

- training activities and materials should be funded to ensure availability of educational opportunities statewide, and training materials should address the needs of: rural areas; non-English speaking Californians; working caregivers; AIDS dementia; and substance abuse and head injury;
- a survey of state employees be conducted to determine the number of working caregivers and program interventions be developed to meet the growing needs of caregivers in the workplace;
- a centralized data retrieval system for acquired cognitive impairments be established; and
- further local and state collaborative efforts be developed to ensure coordination and integration of services and funding.

Annual Report of Programs Under Chapter 1658 of 1984 for Brain-Impaired Adults and Their Families, Year Three, January 1, 1987 Through December 31, 1987, Family Survival Project for Brain-Damaged Adults, 44 Page Street, Suite 600, San Francisco, CA, 94102. [The Annual Reports for 1986 and 1985 are also available.]

Development of a Uniform, Comprehensive Nomenclature and Data Collection Protocol for Brain Disorders, 1986, by David A. Lindeman, Nancy Gourash Bliwise, Gale Berkowitz and Shirley Semple, Institute for Health & Aging, University of California, San Francisco, San Francisco, CA, 94143.

Employed Caregivers of Brain-Impaired Adults: An Assessment of the Dual Role, A Final Report Submitted to The Gerontological Society of America, 1986 Fellowship Program in Applied Gerontology, Funded by the Administration on Aging, February, 1987, Robert B. Enright, Jr., Ph.D., Fellow, and Lynn Friss, M.S.W., Family Survival Project.

Estimating the Utilization and Costs of Formal and Informal Care Provided to Brain-Impaired Adults, Briefing Paper, 1986, by Wendy Max, David A. Lindeman, Tina G. Segura and A. E. Benjamin, Institute for Health & Aging, University of California, San Francisco, San Francisco, CA, 94143.

Copies of these reports can be obtained from Family Survival Project.

[Annual Report of Programs Under Chapter 1658 of 1984 For Brain-Impaired Adults and Their Families, Year Three Jan. 1, 1987 through Dec. 31, 1987, from Family Survival Project, is retained in committee files.]

Chairman MILLER. Dr. Johnson.

STATEMENT OF KENNETH G. JOHNSON, M.D., DIRECTOR, NATIONAL INTERFAITH VOLUNTEER CAREGIVERS PROGRAM, AND ADJUNCT PROFESSOR OF COMMUNITY MEDICINE, MOUNT SINAI SCHOOL OF MEDICINE, NEW YORK, NY

Dr. JOHNSON. Mr. Chairman and other distinguished members of the Select Committee, I will try to summarize the written testimony I submitted.

I would like to call the attention of the committee to the significant contribution that the nation's churches and synagogues and the interfaith caregivers volunteers have made and are capable of making to the care of the family.

My experience is based on that of directing The Robert Wood Johnson Foundation's Interfaith Volunteer Caregivers Program. The Foundation recognized the importance of strengthening the family and its informal support and at the same time recognized the tradition of the churches and synagogues in meeting human needs.

Briefly, the response to the Foundation's announcement was like a clap of thunder. There is a large number of interfaith coalitions in the United States that are willing to engage in caregiving. Only 25 applicants were able to be funded, but 100 more went without. You have a map and a description of these 125 Interfaith Volunteer Caregiver projects.

We have very good data on the 25 funded projects and we have some data on the others. About the 25, I think it is significant that they comprise some 900 congregations of all faiths, and that they have recruited over 10,000 volunteers in a two and a half year period, trained and engaged them in the ongoing treatment of some 26,000 people who are seriously impaired and often isolated.

The project support, which was $50,000 a year each for three years, has long since gone. But I would like to say that all have survived with other means of support that we can discuss with you later, and in fact they have perpetuated the interfaith caregiving with the development of a National Federation of Interfaith Volunteer Caregivers, with Arthur Flemming as Chairman, Virginia Schiaffino as Executive Director. The Federation has a current membership of over 200.

The interfaith volunteer caregivers are engaged in ministry—dedicated, knowledgeable, helpful friends of the families they serve. They have been welcomed by the formal agencies in their communities. They are not considered a threat. They respond to the needs of all disabled people without reference to age, gender or which church you may or may not attend. They are family members; they are friends. They do what family members do: a car trip to the doctor's, straightening up the house, relieving a family caregiver, making the connection to services in the community that may be available.

Interfaith volunteers are prayerful people, but they do not evangelize. They spend at least three hours each week with the friends they serve and they do not consider them clients. This large group of volunteers has less than 3 percent attrition per year. They are safe, and in the history of the program there has not been a hint of litigation.

I was asked to cite some examples with reference to services to families with infants and children. They are listed in the written material.

In a project in Eau Claire, Wisconsin, a 26-year-old mother, bedbound with pregnancy complications, was helped with meal preparation and care of her two children on Saturdays and Sundays for a few months.

In Mobile, Alabama, a volunteer stays with a child whose mother is dying in the hospital until the father is able to come home from work. Another volunteer transports a child from school to daycare so that the mother doesn't need to take time off from work.

Volunteers also provide commonly needed respite for parents of handicapped children.

In New Hampshire we hear of volunteers moving a family. The youngest child had contracted lead poisoning in the old apartment but the family did not have the money to move to a new apartment. The volunteers got a donated truck and moved the family for free.

In New Haven, Connecticut, an 11-year-old girl, chronically ill, whose mother works full-time—a volunteer takes the girl to the doctor, for hospital appointments, and also spends time with her.

Here in Washington we have a very active project, S.O.M.E., So Others May Eat. An example there would be for a poor family—a Self Help Food Club * * * a food co-op, another program of interfaith volunteers. S.O.M.E. provides job counseling, a program to assist women in the neighborhood.

There are other examples cited in the written testimony that I will not go into it at this time.

The Interfaith Volunteer Caregivers Program has been declared successful, on the basis of independent research, in terms of substance and quality. Two reasons were cited by the researchers. One is its level of organization and the fact that an interfaith volunteer project employs a full-time director—and, that provision is made for training and continuing support of volunteers in their work.

We have found that in order to develop a project of substance and provide participating congregations an opportunity and a lead time to gather needed long-term financial support, that about $20,000 in seed money is required. Another thing we have learned is that congregations are a rich source of caregivers. Women employed outside the home represent almost 40 percent of interfaith volunteers. The old, the young, men and women, all have provided important and valued help to families coping with disability.

We have great hopes that the new Federation will establish its objective of promoting and assisting in the establishment of many more Interfaith Volunteer Caregiver projects throughout this country.

The Federation has a goal of making caregiving by churches and synagogues a national movement. I know that this committee shares with interfaith caregiving the common vision of helping families.

I just want to bring to your attention the enormous work that is being done by the interfaith congregations, to point to the great potential that such congregations can provide and also to state that I believe it is in the best interests of our nation to create in as many ways as possible a caring environment for these families.

I think volunteers from interfaith congregations have a particularly strong contribution to make.

[Prepared statement of Kenneth G. Johnson, M.D., follows:]

Prepared Statement of Kenneth G. Johnson, M.D., Director, National Interfaith Volunteer Caregivers Program, Adjunct Professor of Community Medicine, the Mount Sinai School of Medicine, New York, NY

INTRODUCTION

My testimony before the House Select Committee on Children, Youth and Family derives mainly from my experience, beginning in 1984, of directing The Robert Wood Johnson Foundation's national Interfaith Volunteer Caregivers Program.

In the design of the program, the primacy of the family as the major caregiver to disabled members of all ages was recognized. The program also recognized the tradition, as old as the nation, of faith congregations in the U.S. to minister to the needs and suffering of others.

We recognized that societal changes - well described in previous testimony before this committee - had put stress on all families, and especially on families caring for disabled members. Such care is given all day, every day - most often by the mother who is a daughter, trying to manage as best she can and with little respite from her responsibilities, inside and outside the home.

We also recognized limits. The limited access to services to families with low income but not poor enough for Medicaid. The limitation of a professional caregiver to provide sustaining friendship and support. Our best answer to the question: "Who are out there who can be counted on to support this family without reference to eligibility and income?" called for a saintly response: U.S. faith congregations.

I should like to add to this introduction that a single person living in isolation is also a family - a family that was and that needs restitution.

THE INTERFAITH VOLUNTEER CAREGIVERS PROGRAM

The Interfaith Volunteer Caregivers Program was announced in April 1983. The program called for interfaith coalitions of churches and synagogues in a defined community to recruit, train and supervise volunteers who would serve disabled persons of all ages. Among the applications twenty-five would be selected, each to receive $50,000 per year over a three-year period.

Within a brief period (April-July), Over 1,000 requests for application material were received and some 350 completed applications were received. I mention these data because, in reference to other programs, the repsonse was overwhelming - a surprise not unlike a clap of thunder. Among faith congregations - among the 120 million Americans who worship regularly - there are many ready to help.

Twenty-five were funded. The selection made by the advisory committee, chaired by Arthur Flemming, was very difficult. Fortunately, over 100 unsuccessful applicants refused to quit and eventually established interfaith volunteer caregivers projects with other support. The distribution of the 125 projects is shown in Figure 1.

The program began in March 1984. Within a remarkably short time - a matter of four to five months - most of the 25 projects were in operation - with a full-time director, the first volunteers recruited and trained, and the first families served.

At the end of two and one half years, the 25 projects had recruited over 10,000 volunteers who had served over 26,000 persons. Among the 26,000, over 2,000 were infants and children - a proportion that one would expect in a program serving disabled people of all ages. Less than 25% of persons served received care from a formal agency. The evaluation of the program, done by Fordham University's Third Age Center, did not extend beyond the 25 funded projects, but our survey of the other 100 in August 1986 provides an estimate of an additional 50,000 persons being served.

Foundation funding was exhausted by late 1987, but all 25 projects continue. New projects have been established with the technical assistance that we provided during 1987 and 1988 in conference-workshops in California, Wisconsin, New York, Georgia and Florida. Further, from the grass roots of Interfaith Caregiving the National Federation of Interfaith Volunteer Caregivers was established in January 1988 and now has over 200 organizational and individual members.

In the 25 IVCP projects:

- About 900 congregations participated. The major Protestant denominations, Roman Catholic, Jewish and others, including the Buddhist and Bahai faiths.
- Volunteers came in all ages. Fourteen percent were 29 years of age or younger, 53% were over 50 years of age.
- Volunteers helped like family members. Transportation, friendly visits, advocacy and referral to formal services, shopping, homecare, telephone reassurance, chore_services, respite care, meal preparation - were the most frequently given services.
- Volunteers developed strong bonds of friendship with the families they served.

In reference to services to families with infants and children:

From the project in Eau Claire, Wisconsin

A 26-year old mother on Eau Claire's north side, bedbound with pregnancy complications, was helped with meal preparation and care of her two children on Saturdays and Sunday morning for a few months.

From the IVCP project in Mobile, Alabama

A volunteer stays with a child whose mother is dying in the hospital until the father comes home from work.
Another volunteer transports a child from school to day care so that the mother does not need to take time off from work.
Volunteers will also provide respite for parents of handicapped children.

From the IVCP project in Manchester, New Hampshire

Volunteers moved a destitute family for free. The youngest child had lead poisoning from the old apartment, but the family did not have the money to move to a new apartment. Volunteers did the work with a donated truck.

From the IVCP project in New Haven, Connecticut

A volunteer is matched with an 11-year-old girl who is chronically ill. Her mother works full-time. The volunteer takes the girl to doctor and hospital appointments and also spends time with her.

The IVCP project in Washington, DC (S.O.M.E.) seeks to develop leadership in the community by involving families in programs that will assist them.

A Self Help Food Club has approximately 80 participating families who are at or just above the poverty line. Members pay a $3/month fee, and help to sort and bag food. Membership includes nutritional counseling and learning how to shop.

The Food Co-op to which approximately 40-70 families belong, teaches people how to run a small business and is the only source of fresh fruits and vegetables in the area.

Other S.O.M.E. programs include: job counseling, "Just for Women," a program to assist women in the neighborhood, helping them to draw support from one another and workshops conducted on parenting skills, budgeting, cleaning, nutrition, and drug and alcohol abuse.

The IVCP project in Yakima, Washington has established a Respite Adult Day Center in one of the local churches. The Center is staffed by volunteers and allows family members to work or receive a brief rest from their caregiving duties.

Volunteers also provide respite care and transportation to doctors' appointments for children.

The IVCP project in Lewiston, Idaho

Services to children most often include transportation to needed medical services. Many families live in rural, isolated areas and have to go across the state border to Washington for medical appointments.

The local hospital will also request volunteers to assist with young pregnant mothers who need to remain in bed or who have experienced the loss of their fetus or newborn. Volunteers care for other children in the family and provide support to the women and their husbands.

- The IVCP project in Honolulu, Hawaii

Families coming from Guam for medical care in Hawaii are helped by the IVCP. Volunteers provide temporary housing and transportation to medical appointments.

WHAT HAVE WE LEARNED FROM IVCP?

We know that U.S. faith congregations are an enormous resource that can be tapped - given the proper stimulus and modest assistance. The stimulus is an invitation for them to exercise a spiritual ministry. The assistance is some $20,000 in seed money, the first dollars to recruit a full-time director and set up shop to train volunteers. With all other claims on church funds, outside first dollars are required to put in place a project with substance, in which volunteers are trained and sustained. We know that given a sufficient "lead time" to demonstrate the effectiveness of the program, local continuing support will be forthcoming.

We have learned that the interfaith volunteer is an able and dedicated friend to the family, a relationship with a low burn-out, one that you can depend on.

We have noted an apparent immunity from legal litigation that volunteers enjoy in their helping others. Not a hint of litigation during the life of the program. Good friends are unlikely to sue good friends.

We have learned that we need not be anxious about the loss of volunteers to employment outside the home; nor should we pay much attention to the commonly held stereotypes of volunteers. Women who work full-time outside the home represent almost 40% of interfaith volunteers. About one-third of the volunteers are 65 years of age and over. Men serve in all sorts of ways: they provide transportation, repair homes, deliver meals, lift people out of bed, follow through on prescribed rehabilitative exercises, give baths and shaves. Almost 15% of the volunteers are the young - doing everything from house clean-outs to fund raising walk-a-thons and car washes. Eighty percent of the volunteers in the 25 funded IVCP projects were recruited from faith congregations. For most, it was a case of putting their faith into action.

HOW SHOULD GOVERNMENT VIEW INTERFAITH CAREGIVING?

I believe that interfaith caregiving should be recognized for the important and substantial service that it now provides for troubled families, and for its potential to do so much more. The 120 million Americans in congregations whose faiths direct them to serve others are an enormous national resource.

Interfaith caregiving is consonant with services provided by Government in that no person is excluded from care on the basis of age, sex, color or religious determination. In the IVCP, whites and blacks give and receive; Buddhists care for Christians; Catholic nuns minister to elderly Jewish men. The IVCP has always recognized that those families most in need are the forgotten, the dimly churched and the un-churched. Interfaith volunteers do not engage in evangelization.

Interfaith volunteers, always supported by health and social service professionals, are not their substitutes, However, as a knowledgeable and caring family friend, the volunteer is a God-send to families in need. The volunteers do what they can and know the many places in the community where other help may be available.

I can point to one state - the State of Washington - in which state support for interfaith caregiving has stimulated the establishment of projects throughout the state. The money allocation - a smaller substitute for stopping reimbursement for chore services - was first made to Area Agencies on Aging. The AAA'S declined and the funds were then distributed to statewide agencies, mainly Catholic Community Services. As a fiscal agent, Catholic Community Services in turn enabled interfaith volunteer caregivers projects to be established.

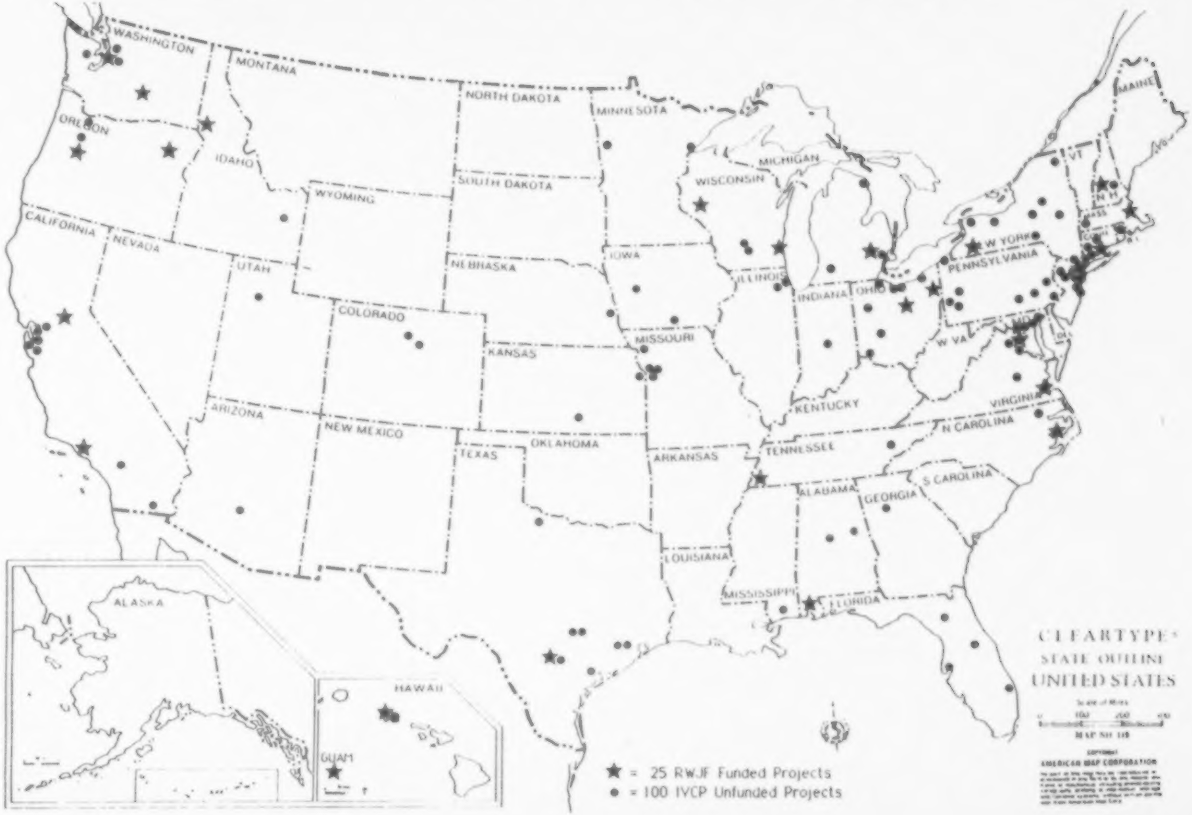
Assisting children, youth and families - specifically, in strengthening important informal supports - calls for a multi-generational solution. We need the mature older person to comfort and teach the disabled child, and to support other family members. Older women - as "resource mothers" - help teenagers who are pregnant to care for themselves and their infants and to approach the rest of life with hope. I make this point to call attention to the interrelatedness and interdependency between programs relating to maternal and child health services and those relating to support for older Americans. In the IVCP, no discrimination between generations has been made; age in reference to disability has not been considered to be a relevant or constraining issue.

To sum, in this testimony I bring to the attention of the Committee information on a national effort of interfaith volunteer caregiving. Interfaith volunteers have served and continue to serve thousands of disabled persons - and their families - of all ages, with great safety and comfort and without charge. The mainspring of interfaith caregiving is the commonly held exhortation of all denominations to serve people in need, whoever they are and wherever they may be.

Government and interfaith caregiving share the common vision of helping children, youth and families within the constraints of resources. Within the polyglot of assistance required by persons and families who live with disability, the services of the interfaith volunteer as a knowledgeable and able advocate and friend are both efficient and effective, especially needed by families ineligible for public assistance.

FIGURE 1

Interfaith Volunteer Caregivers Program


WASHINGTON
MONTANA
NORTH DAKOTA
MINNESOTA
MAINE
OREGON
IDAHO
WYOMING
SOUTH DAKOTA
WISCONSIN
MICHIGAN
VT
N H
MASS
W YORK
PENNSYLVANIA
CALIFORNIA
NEVADA
UTAH
NEBRASKA
IOWA
ILLINOIS
INDIANA
OHIO
COLORADO
KANSAS
MISSOURI
W VA
KENTUCKY
VIRGINIA
N CAROLINA
TENNESSEE
ARIZONA
NEW MEXICO
OKLAHOMA
TEXAS
ARKANSAS
ALABAMA
GEORGIA
S CAROLINA
LOUISIANA
MISSISSIPPI
FLORIDA
ALASKA
HAWAII
GUAM
★ = 25 RWJF Funded Projects
● = 100 IVCP Unfunded Projects
CLEARTYPE
STATE OUTLINE
UNITED STATES
AMERICAN MAP CORPORATION

THE ROBERT WOOD JOHNSON FOUNDATION'S
25 INTERFAITH VOLUNTEER CAREGIVERS PROJECTS

Caregivers, Inc.
Mobile, AL

Interfaith Volunteer Caregivers Project
Sacramento, CA

Buenaventura Interfaith Volunteer
Caregivers Project
Ventura, CA

Interfaith Volunteer Caregivers Project
New Haven, CT

Interfaith Volunteer Caregivers Project
Washington, DC

Interfaith Volunteer Caregivers, Inc.
Guam, GU

Project RESPECT
Honolulu, HI

Project Interlink
Lewiston, ID

Match-Up
Boston, MA

Interfaith Volunteer Caregivers Project
Pontiac, MI

Interfaith Volunteer Caregivers Project
Belhaven, NC

The CAREGIVERS
Manchester, NH

Interfaith Volunteer Caregivers Project
New York, NY

Interfaith Volunteer Caregivers Project
Olean, NY

Akron Area Interfaith Volunteer
Caregivers Project
Akron, OH

Volunteer Service to Seniors
Youngstown, OH

Interfaith Volunteer Caregivers Project
Albany, OR

Neighbor to Neighbor Ministries
La Grande, OR

Caregivers Coalition
Memphis, TN

Jefferson Area CO-OP
San Antonio, TX

Norfolk Interfaith Coalition
for the Elderly
Norfolk, VA

Interfaith Volunteer Caregivers Project
Seattle, WA

Interfaith Volunteer Services
Yakima, WA

Triniteam Caregivers Program
Eau Claire, WI

Interfaith Program for the Elderly
Milwaukee, WI

Chairman MILLER. Ms. Brody.

STATEMENT OF ELAINE M. BRODY, ASSOCIATE DIRECTOR OF RESEARCH, PHILADELPHIA GERIATRIC CENTER, PHILADELPHIA, PA

Ms. BRODY. Thank you.

Almost a decade ago, the findings of a Philadelphia Geriatric Center—PGC—research study led us to characterize daughters who take care of their disabled elderly parents as "women in the middle." It is daughters who, in the main, help the elderly care for their disabled spouses. It is the daughters who are the primary helpers to the severely disabled elderly who, because of their very advanced ages, are less likely to have a surviving spouse to provide or share caregiving tasks. It is mainly daughters who share their homes with elderly parents when those parents can no longer manage alone.

The 1982 Long Term Care Survey sponsored by the Department of Health and Human Services found that daughters provide more than half of the long-term care services received by the most severely disabled elderly, including personal care, household maintenance, transportation and shopping.

It is the very old—people 75 years of age and over, and 85 and over—who have increased at the fastest rate of any age segment in the population, and that trend will continue. Another demographic trend that has a direct effect on filial caregiving has been the falling birthrate. The net result is that older people nowadays have fewer adult children to share caregiving responsibilities than used to be the case.

More daughters nowadays provide more care and more intensive care to more older people over longer periods of time than ever before in history. And because the ailments and disabilities of the old are chronic, that care often must be provided for many years.

Despite the increased need for parent care that confronts modern families, they have been steadfast and reliable helpers. They, not government or community agencies, provide the vast majority of the supportive services received by disabled elderly. The LTC Survey found that less than 15 percent of all "helper days" of care to severely disabled old people are provided by the formal system.

The social, emotional and economic costs to families of providing care are enormous. A consistent body of research has shown that the most pervasive and severe effects on caregivers, affecting half to three-fourths of them, are mental health symptoms such as depression, anxiety, sleeplessness, frustration and lowered morale. Smaller but significant proportions report deterioration in their physical health or economic strain.

Some daughters have caregiving careers. In our studies, two-thirds of those helping widowed elderly mothers had also helped their fathers before the latter died; one-third had helped other elderly relatives other than their own parents in the past; and 22 percent of all the caregiving daughters were currently helping more than one elderly relative.

Recently information has been emerging about additional problems experienced by those caregivers who are in the labor force.

Middle-aged women have accounted for the largest increase in labor force participation. Most such women now work, and they are the ones most likely to have parent care responsibilities. Parent-caring women, however, can be at different stages of life. As many as one-third are either under 40 or over 60.

The woman in the middle may have her own young children at home. She may be at the time of life when her children have grown and left the nest, only to have that nest refilled with a disabled parent. Or she may be a grandmother who is in the aging stage of life.

Whether or not they are employed, daughters struggle to fulfill their responsibilities to their families, homes, jobs and elderly parents, giving up only their own free time in the process.

Our studies have shown that elderly parents of employed women do not receive less care than parents of women who do not do out-of-home work. When some paid help is needed by employed women to care for the parent during work hours, it is paid for by the older people and their families, not by the government.

We found that 13 percent of parent-caring women in our sample had found it necessary to quit their jobs and they were the ones who could least afford to do so; 40 percent of them had family incomes of less than $15,000 a year. In addition, about one-quarter of the parent-caring women who were employed had either reduced their working hours or were considering quitting; they were having problems such as losing time from work and job interruptions.

The 1982 LTC Survey confirmed these data, finding that 11.6 percent of caregiving daughters and similar proportions of elderly spouses as well had left their jobs to take care of their dependent elderly; some sons, too, did so, but to a lesser extent.

In the Travelers Employee Survey, June 1985, and surveys at other work sites, at least 20 percent of employees were helping an elderly relative. The Conference Board has called the problems of employees helping elderly relatives "a bottom-line business concern."

Virtually nothing is known about the opportunity costs to people who quit their jobs or reduce their working hours, though in one study caregivers who were deterred from working estimated their lost earnings at an average of $20,000 annually.

Caregiving daughters who experience such problems and stress effects are not only in the middle in being the middle generation; they are in the middle of multiple competing demands on their time and energy. Many are also in the middle between competing values and needs—the value to which they are committed that family care of the elderly is a family responsibility and the value that it is all right for women to work outside the home. It should be emphasized that most employed women work because they and their families need the money they earn.

It is most appropriate that this hearing is being held by the Select Committee on Children, Youth and Families, for data is piling up showing the effects of caregiving on the entire family. Sons, too, become caregivers, primarily when they have no sisters or none close by.

Whether the filial caregiver is a daughter or a son, the family's lifestyle, socialization, privacy and even future plans are affected.

Sons-in-law, too, experience strains when their wives are caregivers. The caregiver's siblings are also affected, even those who live far away and therefore have special problems. The lives of grandchildren are affected, no matter what their age; those who are grown often act as a backup system of care. When the disabled old person lives with the daughter and her family, relationship problems are more likely to develop among the members of the different generations.

Let me turn for a moment to one of the family-focused services that could alleviate some of the problems, a service that is badly needed as part of a long-term care system. I refer to respite service, that is, any service or group of services designed to provide temporary periods of relief or rest for caregivers away from the patient. Examples are in-home care, temporary nursing home care and daycare.

At the PGC, Dr. M. Powell Lawton, Ms. Avalie Saperstein and I recently completed the only controlled demonstration/research study of respite for caregivers of Alzheimer's patients, financed by grants from the John A. Hartford Foundation, Inc., of New York, and the Pew Charitable Trusts of Philadelphia.

I will summarize a few of our major findings.

Most caregivers must be educated about what respite care is and how to use it. Most view it as a last-ditch service to be used when they are on the verge of breakdown.

The offer of respite did not unleash an unmanageable and costly demand, as policymakers often fear. Only half of caregivers who were offered respite availed themselves of the subsidized service; they used it very sparingly and were eager to pay whatever they could.

Families who use the respite services did not reduce the amount of family help they provided.

Given the choice of in-home respite, daycare and institutional respite, in-home proved to be the most popular, chosen by two-thirds of our caregivers. The three types of respite were all important, however, with each meeting different needs of families in different situations at different times.

As compared with a control group of caregivers who were not offered respite, those who were offered respite maintained their patients in the community for a somewhat longer period of time—a modest increment of 22 days.

As in other respite demonstrations, the caregivers gave the service a resounding endorsement, reporting that they had received relief, were satisfied and wished for additional respite in the coming year more than they wished for any other service.

We consider it of major importance that respite service must be part of a total long-term care system. Since respite is never the only service needed, the respite program itself should include at the least: careful assessment of the patient and family; caregiver education about respite and other services, about the ailments of the older person, and about caregiving techniques; skilled counseling; and case management to link the family to other existing services and to monitor the situation over time.

The family's caregiving crunch is likely to worsen in the future, increasing the urgency of developing a long-term care system that includes both quality nursing home care and quality community services.

Barring major biomedical breakthroughs that would prevent or mitigate the major disabling diseases of old age, such as Alzheimer's disease, the number of disabled very old people will increase. It is obvious that spouses of such people are themselves in advanced old age and most of their adult children are likely to be in middle or early old age.

Other trends have been occurring that undoubtedly will affect patterns of family care and the experiences of women in the middle.

Since rates of disability are highest among very old people and rates of widowhood begin to soar during middle age, adult daughters will be more likely to be widows. Combined with the increase in the divorce rate and the increasing tendency for women to remain unmarried, this means that more filial caregivers will be women who are not married and are more likely to be in the labor force.

The data are already showing that trend. In the 1982 Long Term Care Survey, 44 percent of daughter caregivers were not married, a marked contrast from 25 years ago when three-quarters of the people, other than spouses, to whom older people would turn in a health crisis were married women.

There are other relevant trends. Developmentally disabled children live longer nowadays, increasing the number of women who must care for them as well as for elderly parents.

As more people live well into advanced old age, the changes increase of losing a supportive adult child through death. In such instances, grandchildren, particularly granddaughters, often fill the generational gap by caring for grandparents. Some women in the middle provide help to their parents and grandparents as well as to their own children.

Because of the low birthrate, in the future more old people will have no children and more will have only one child. Fewer children means fewer daughters. Moreover, women are often daughters-in-law as well as daughters. Since daughters-in-law often fill in when there are no daughters, more women may find themselves providing care to elderly parents-in-law as well as parents.

Because of increasing mobility, geographic distance will handicap more people in their efforts to care for their parents.

Finally, a significant trend is the tendency for people nowadays to have a first child at later ages, in their 30s and even 40s, so that they may need to provide parent care at a time when they have young children at home.

I respectfully suggest that provision of help to family caregivers should be a high priority concern for social policy and that the major form of help needed is federally financed long-term care insurance covering nursing home care as well as community care.

Thank you for the opportunity to present this information.

[Prepared statement of Elaine Brody follows:]

PREPARED STATEMENT OF ELAINE M. BRODY, PHILADELPHIA GERIATRIC CENTER, PHILADELPHIA, PA

Almost a decade ago, the findings of a Philadelphia Geriatric Center (PGC) research study led us to characterize daughters who take care of their disabled elderly parents as women-in-the-middle. It is daughters who, in the main, help the elderly care for their disabled spouses. It is the daughters who are the primary helpers to the severely disabled elderly who, because of their very advanced ages, are less likely to have a surviving spouse to provide or share caregiving tasks. It is mainly daughters who share their homes with elderly parents when those parents can no longer manage alone. The 1982 Long Term Care Survey sponsored by the Department of Health and Human Services found that daughters provide more than half of the long term care services received by the most severely disabled elderly (Stone et al., 1987), including personal care, household maintenance, transportation and shopping.

It is the very old -- people 75 years of age and over and 85 and over -- who have increased at the fastest rate of any age segment in the population and that trend will continue. Another demographic trend that has a direct effect on filial caregiving has been the falling birthrate. The net result is that older people nowadays have fewer adult children to share caregiving responsibilities than used to be the case. More daughters nowadays provide more care and more intensive care to more older people over longer periods of time than ever before in history. And, because the ailments and disabilities of the old are chronic, that care often must be provided for many years.

Despite the increased need for parent care that confronts modern families, they have been steadfast and reliable helpers. They, not government or community agencies, provide the vast majority of the supportive services received by disabled elderly. The LTC Survey found that less than 15% of all "helper days" of care to severely disabled old people are provided by the formal system (Doty et al., 1985).

The social, emotional, and economic costs to families of providing care are enormous. A consistent body of research has shown that the most pervasive and severe effects on caregivers, affecting half to three-fourths of them, are mental health symptoms such as depression, anxiety, sleeplessness, frustration, and lowered morale; smaller, but significant proportions report deterioration in their physical health or economic strain. Some daughters have caregiving careers: in our studies two-thirds of those helping widowed elderly mothers had also helped their fathers before the latter died; one-third had helped other elderly relatives other than their own parents in the past; and 22% of all the caregiving daughters were currently helping more than one elderly relative.

Recently, information has been emerging about additional problems experienced by those caregivers who are in the labor force. Middle aged women have accounted for the largest increase in labor force participation. Most such women now work, and they are the ones most likely to have parent care responsibilities. Parent caring women, however, can be at different stages of life. As many as one-third are either under 40 or over 60. The woman in the middle may have her own young children at home; she may be at the time of life when her children have grown and left the nest, only to have that nest refilled with a disabled parent; or she may be a grandmother who is in the aging stage of life. Whether or not they are employed, daughters struggle to fulfill their responsibilities to their families, homes, jobs, and elderly parents, giving up only their own free time in the process. Our studies have shown that elderly parents of employed women do not receive less care than parents of women who do not do out of home work. When some paid help is needed by employed women to care for the parent during work hours, it is paid for by the older people and their families, not by government.

We found that 13% of parent caring women in our sample had found it necessary to quit their jobs and they were the ones who could least afford to do so; 40% of them had family incomes of less than $15,000 a year. In addition, about one-quarter of the parent caring women who were employed had either reduced their working hours or were considering quitting; they were having problems such as losing time from work and job interruptions (Brody, 1985). The 1982 LTC Survey confirmed these data, finding that 11.6% of care-giving daughters and similar proportions of elderly spouses as well had left their jobs to take care of their dependent elderly; some sons, too, did so, but to a lesser extent (Stone et al., 1987). In the Travelers Employee Survey (June 1985) and surveys at other work sites (AARP, Feb. 1987) at least 20% of employees were helping an elderly relative. The Conference Board has called the problems of employees helping elderly relatives "a bottom-line business concern" (Friedman, 1986).

Virtually nothing is known about the opportunity costs to people who quit their jobs or reduce their working hours, though in one study (Enright and Friss, 1987) caregivers who were deterred from working estimated their lost earnings at an average of $20,000 annually.

Caregiving daughters who experience such problems and stress effects are not only in the middle in being the middle generation. They are in the middle of multiple competing demands on their time and energy. Many are also in the middle between competing values and needs -- the value to which they are committed that family care of the elderly is a family responsibility and the value that its all right for women to work outside the home. It should be emphasized that most employed women work because they and their families need the money they earn.

It is most appropriate that this hearing is being held by the Select Committee on Children, Youth, and Families, for data is piling up showing the effects of caregiving on the entire family. Sons, too, become caregivers, primarily when they have no sisters or none close by. Whether the filial caregiver is a daughter or a son, the family's life-style, socialization, privacy and even future plans are affected. Sons-in-law, too, experience strains when their wives are caregivers. The caregivers' siblings are also affected -- even those who live far away and therefore have special problems. The lives of grandchildren are affected, no matter their age; those who are grown often act as a back-up system of care. When the disabled old person lives with the daughter and her family, relationship problems are more likely to develop among the members of the different generations.

Let me turn for a moment to one of the family-focused services that could alleviate some of the problems, a service that is badly needed as part of a long term care system. I refer to respite service -- that is, any service or group of services designed to provide temporary periods of relief or rest for caregivers away from the patient. Examples are in-home care, temporary nursing home care, and day care. At the PGC, Dr. M. Powell Lawton, Ms. Avalie Saperstein, and I recently completed the only controlled demonstration/research study of respite for caregivers of Alzheimer's patients, financed by grants from the John A. Hartford Foundation, Inc., of New York and the Pew Charitable Trusts of Philadelphia. To summarize a few of our major findings:

. Most caregivers must be educated about what respite care is and how to use it. Most view it as a last ditch service to be used when they are on the verge of breakdown.

. The offer of respite did not unleash an unmanageable and costly demand as policy makers often fear. Only half of caregivers who were offered respite availed themselves of the subsidized service, they used it very sparingly, and were eager to pay whatever they could.

. Families who use the respite services did not reduce the amount of family help they provided.

. Given the choice of in-home respite, day care, and institutional respite, in-home proved to be the most popular, chosen by two-thirds of our caregivers. The three types of respite were all important, however, with each meeting different needs of families in different situations at different times.

. As compared with a control group of caregivers who were not offered respite, those who were offered respite maintained their patients in the community for a somewhat longer period of time (a modest increment of 22 days).

. As in other respite demonstrations, the caregivers gave the service a resounding endorsement, reporting that they had received relief, were satisfied, and wished for additional respite in the coming year more than they wished for any other service.

We consider it of major importance that respite service must be part of a total long-term care system. Since respite is never the only service needed, the respite program itself should include at the least: careful assessment of the patient and family; caregiver education about respite and other services, about the ailments of the older person, and about caregiving techniques; skilled counselling; and case management to link the family to other existing services and to monitor the situation over time.

The family's caregiving crunch is likely to worsen in the future, increasing the urgency of developing a long-term care system that includes both quality nursing home care and quality community services. Barring major bio-medical breakthroughs that would prevent or mitigate the major disabling diseases of old age (such as Alzheimer's disease), the number of disabled very old people will increase. It is obvious that spouses of such people are themselves in advanced old age and most of their adult children are likely to be in middle or early old age.

Other trends have been occurring that undoubtedly will affect patterns of family care and the experiences of women in the middle. Since rates of disability are highest among very old people and rates of widowhood begin to soar during middle age, adult daughters will be more likely to be widows. Combined with the increase in the divorce rate and the increasing tendency for women to remain unmarried, this means that more filial caregivers will be women who are not married and are more likely to be in the labor force. The data are already showing that trend. In the 1982 Long Term Care Survey, 44% of daughter caregivers were not married (Stone et al., 1987), a marked contrast from 25 years ago when three quarters of the people (other than spouses) to whom older people would turn in a health crisis were married women (Shanas, 1961).

There are other relevant trends:

. Developmentally disabled children live longer nowadays, increasing the number of women who must care for them as well as for elderly parents.

. As more people live well into advanced old age, the chances increase of losing a supportive adult child through death. In such instances, grandchildren, particularly granddaughters, often fill the generational gap by caring for grandparents. Some women in the middle provide help to their parents and grandparents as well as to their own children.

. Because of the low birthrate, in the future more old people will have no children and more will have only one child. Fewer children means fewer daughters. Moreover, women are often daughters-in-law as well as daughters. Since daughters-in-law often fill in when there are no daughters, more women may find themselves providing care to elderly parents-in-law as well as parents.

. Because of increasing mobility, geographic distance will handicap more people in their efforts to care for their parents.

. Finally, a significant trend is the tendency for people nowadays to have a first child at later ages, in their 30s and even 40s, so that they may need to provide parent care at a time when they have young children at home.

I respectfully suggest that provision of help to family caregivers should be a high priority concern for social policy and that the major form of help needed is federally financed long-term care insurance covering nursing home care as well as community care. Thank you for the opportunity to present this information.

References

AARP (American Association of Retired Persons). Caregivers in the Workplace, Survey Results, Overall Summary, Washington, DC, Februrary 1987.

Brody, E.M. Parent care as a normative family stress. The Donald P. Kent Memorial Lecture, The Gerontologist, 1985, 25, 19-29. In Troll, L.E. (Ed.), Family Issues in Current Gerontology, Springer Publishing Co., New York, 1986, 97-122.

Doty, P. Family care of the elderly: The role of public policy. The Milbank Quarterly, 1986, 64, No. 1.

Doty, P., Liu, K., & Wiener, J. An overview of long-term care, Health Care Financing Review, 1985, 6, 69-78.

Enright, R.B., & Friss, L. Employed Caregivers of Brain-Impaired Adults, Family Survival Project, San Francisco, CA, Feb. 1987.

Friedman, D.E. Elder Care: The Employee Benefit of the 1990s?, in Across the Board, June 1986, 46-51.

Shanas, E. Family Relationships of Older People. Health Information Foundation, Research Series 20. University of Chicago, Chicago, IL, 1961.

Stone, R., Cafferata, G.L., & Sangl, J. Caregivers of the frail elderly: A national profile, The Gerontologist, 1987, 27, 616-626.

STATEMENT OF J. KNOX SINGLETON, CHAIRMAN, VOLUNTEER DEVELOPMENT COMMITTEE, FAIRFAX COUNTY COMMISSION ON AGING, FAIRFAX, VA

Mr. SINGLETON. I am honored to speak to you on behalf of the stressed families who have multigenerational caring responsibilities.

I don't think I can add anything to the description of the dimensions of the problem that were given and the very excellent initial statement that the Chairman made and the eloquent testimony we have heard from the families and others up to this point.

There is no question but that it is a tremendous problem. I have talked with literally hundreds of adults in situations such as have been described. As I see it, they are trying to categorize the needs of basically four types that I see.

The first is one of information, education and counseling on a wide range of concerns, such as health care, living arrangements, financial, legal, family relationships, et cetera.

Second, they need respite from their caregiving responsibilities if their physical and mental health is to be maintained.

Third, they need assistance with many of the caregiving tasks that they are called on to render.

Fourth, they need financial assistance when their income is limited and the cost of care exceeds the financial resources of their parents.

So those are the four main categories of need, as I see them.

The question is, how do we address these needs? First of all, I would like to say that I see that there is a definite limitation on the amount of services that the government can provide directly to these families. I think that the major resource or approach that I see is one that Dr. Johnson has addressed, and that is through the organization of community-based programs involving the churches and older adults principally as volunteers, but also to the extent that younger persons are able or in a position to participate.

Adult children cannot cope with multigenerational dependent care alone. The involvement of volunteers and community-based services are critical to alleviating the stress of the "sandwich generation," particularly the women in the middle. There is a definite limitation in what government programs can and should do in the way of human services. Government programs should promote the development of community-based private and volunteer services.

There are organizations of this type. A super example has just been described by Dr. Johnson. There is another program that has come to my attention that I think is exemplary, the Shepherd Center in the United Methodist Church in Kansas City, replicated in some 70 communities throughout the country. I see a great need to try to recreate the sense of caring communities that we have lost largely through our employment mobility, separating the families so that they are not oftentimes in proximity to reasonable care, and then to the employment of women, the caregivers who have been lost. So we are called on to recreate the sense of caring and to supplement the services that are needed.

We have not begun to recognize the tremendous potential that resides among the older persons retiring at 55 or 60 and living another 20 to 25 years. They are largely not employed to anywhere near their potential. I think we need to make a great effort to encourage community-based programs involving the churches and particularly involving older adults in the responsibility of providing the family support programs that are so much needed to supplement or complement the government services.

Mental health programs and area agencies on aging provide the kind of services that are needed, the information, education, training, counseling—being trained in these areas.

I have personally been involved in helping older adults. They can be trained to help families. So that is one great need that can be met. They can provide the kinds of respite care that is so desperately needed, as has been cited, and they can help in the day-to-day tasks, the transportation and home care kinds of things.

These kinds of services are not available and will not be available unless we have a completely socialized system in direct government services, and I don't think we ought to look to that. They are not available often from paid services.

In my suburban community, it is almost impossible to get the services needed in this home support. So this is the direction that I see as absolutely necessary if we are to have the kind of caring communities that are needed to support this.

The government role in this, as I see it, well, it is like training communities and helping persons to help themselves. According to the old adage, you give a man a fish and you have given him a meal for a day; if you teach him to fish, he is set for a lifetime. The government role is in promoting, supplementing. We have the departments and agencies to facilitate a system in the development of these community programs. And then in the area of some kind of help for catastrophic long-term illness that is so devastating, there is a definite role for the government in that respect.

In summary, the community-based programs involving churches and older adults principally are the major resources and this would be the direction that I would recommend to your consideration.

Thank you very much.

Chairman MILLER. Thank you.

[Prepared statement of Julius Knox Singleton follows:]

PREPARED STATEMENT OF JULIUS KNOX SINGLETON, BURKE, VA

My name is Julius Knox Singleton. I appreciate the opportunity to present a brief testimony on one of the very important matters coming before this committee. I understand that the primary focus at this point in your hearings is on the situation that many adult children, especially women, find themselves in when they are confronted with the need to give special attention to their aging parents at the same time that they have a myriad of other family, work and social responsibilities. They are properly labeled the "sandwich generation", and they need help.

Before I proceed with some hopefully helpful suggestions, I think I should briefly describe my qualification to speak on this subject. After thirty years of Federal Service as an electronic engineer, I became a professional counselor specializing in the concerns of aging. Since 1981 I have served on the Fairfax County Commission on Aging, including two terms as Chair. I currently serve as chairman of the Volunteer Development Committee of the Commission. In April, 1984, I organized the all-volunteer Springfield (Virginia) Information and Counseling for Older Adults and Their Families which I continue to coordinate.

From my life and professional experience, I will limit my remarks to the question of "How can we help adult children, expecially the woman, who have to care for aging parents along with their many other responsibilities?" To be helpful we must first understand their needs; and their needs are many. (These need statements characterize the group as a whole; there are individual exceptions, of course. The statements are the briefest summaries I could write. To fully explicate them would require a full chapter, if not a book, on each need.)

1. They need information, education, and counseling on a wide range of concerns (health care, living arrangements, financial, legal, family relationships, etc.).

2. They need respite from their caregiving responsibilities if their physical and mental health is to be maintained.

3. They need assistance with many of the caregiving tasks that they are called on to render.

4. They need financial assistance when their income is limited and the cost of care exceeds the financial resources of their parents.

Concerning these needs, it is my strong opinion that:

A. Adult children cannot cope with multigenerational dependent care alone. The involvement of volunteers and community -based services are critical to alleviating the stress of the "sandwich generation", particularly the women in the middle. There is a definite limitation in what government programs can and should do in the way of human services. Government programs should promote the development of community-based private and volunteer services.

B. There is a huge reservoir of underutilized older adults that needs to be employed in useful work, especially helping families. Policy-makers at all levels of government need to recognize and utilize the tremendous potential of the collective body of older adults. Their services should include peer support for older adults, respite care for family caregivers, child care, information and counseling, home and health care, education, etc. The majority of this service would come from volunteers. Those who need supplemental income could receive modest fees from familites who could afford to pay.

C. In addition to caring for aging parents, the family today is in need of a variety of family support programs, many of which can be delivered by older volunteers. This would provide an intergenerational environment that would have a positive effect on families and serve to strengthen them.

D. Strong encouragement should be given to keeping the elderly out of institutions except in those instances where it is clearly impractical under the existing family circumstances and the health care needs of the elder. Home health care insurance, and possibly tax credit incentives, should be provided where needed to avoid more expensive and less desirable forms of care. Where institutionalization becomes necessary, government sponsored insurance programs should protect the individual and his/her family from pauperization due to the exorbitant cost of long-term institutional care.

These are the principal points that I would recommend for your consideration. I will be pleased to try to answer any questions that you may have. Thank you again for the opportunity to come before you.

Chairman **Miller**. Ms. Frances.

STATEMENT OF DOROTHY FRANCES, FRIENDLY VISITOR, RETIREE SERVICE DEPARTMENT, INTERNATIONAL LADIES' GARMENT WORKERS UNION, NEW YORK, NY

Ms. **Frances**. Good morning. My name is Dorothy Frances and I am 63 years old and a retiree of the International Ladies' Garment Workers Union from New York City, where I am employed by the union as a Friendly Visitor.

As a Friendly Visitor, I visit retired members of the ILGWU, including some who are shut in and who depend on us to help with their daily living activities, such as shopping, doctor's appointments, paying bills and so on.

Let me tell you a little bit about our retirees. They are mostly women—89 percent, their average age is 75 but most of the retirees I see are in their 80s or 90s, and their income is sometimes so low that they have to skimp just to have life for another year. It keeps them going to know they can still save for tomorrow. It is frightening for them to think that since they have gotten older, they need someone to help them.

Most of the retirees I see have children but they don't live in New York. They will call or come to visit, but sometimes only once a month or even once a year. And a lot of them don't see their children from one year to another. Anyway, now that the children are grown, the parents don't want to worry them with their problems. They feel they are intruding into their lives.

I have a blind retiree who calls me a lot. Last week I took her shopping for underwear for next winter. She waited for bargains and we went downtown to Delancey Street and put in a supply for next winter. She is depressed in the last year since she went blind. She is 78 years old and she has a son but she sees him only on holidays. She has been very independent all along and her son has a family of his own, teenagers, and even if he might come and help her out more often, she doesn't like to bother him.

It is people like this who depend on us, the Friendly Visitors, for almost everything. Mostly they are lonely and longing just to spend a little time with you.

Have you ever visited retirees and they tell you when they go to bed at night they pray and ask God to take them in their sleep? I hear this very often. People like this who depend on us, Friendly Visitors, are very lonely day and night. Some nights when they can't sleep, they will call me and we talk a while. My husband calls them my children.

So I think we help all the family, not just the retirees, because we help people to stay more independent. The parents, children, sometimes it is even sisters, nephews, nieces, can call us if they need us and we are there. The children, who have their jobs and their families, need time for themselves, too, without feeling guilty about mother or father.

I visit many retirees who take care of their husbands and it is so hard for them. Their income is maybe $5.00 above Medicaid and they can't get help. The burden is only theirs.

Some of the retirees I see take care of their grandchildren. They come to their house after school or the grandparents pick them up, if they are able. They feel they are helping their children and it is a way for the children not to have to pay for daycare. I have found one or two, you feel sorry for them because they have already raised their children and now they feel burdened by the grandchildren. They have no time to take care of themselves. We, the Friendly Visitors, will always find time for her.

We take a lot of our retirees to the doctor at the ILGWU Health Center. We have good doctors for just about everything. I hope one day we will have a dental clinic. I am proud to see our members take advantage of what our union built for us. One day I saw a retiree at the health center. She seemed to be in her 80s. She was pretty frail. She couldn't have made it there by herself. She seemed to be with her grandson. He was about 22 or 23, but I think he was an addict. You could see it just by looking at him. He was very attentive to his grandmother, but I worried about her having to depend on him. I felt sorry for her. This was the second time I had seen her there.

We have retirees that live in old tenement houses with no elevators, some on the fifth and sixth floor. They cannot get out and must depend on somebody for all their needs. They often ask us, where can we get a doctor for a house call. Today our retirees who can do for themselves are afraid to go out in the streets alone.

We even have situations where two generations of our retirees need our help. A daughter, 62 years old, an Italian lady, is going to have to stop working, even though she loves her job in the Garment Center. She lives with her mother, who is about 85, and they just told her she has Alzheimer's disease. Up until now the daughter has been going to work, leaving food in the refrigerator. Now the mother is getting much worse. She throws food around and spits on everything in the house. So the daughter says she will retire very soon to take care of her mother. She feels she can at least do this for a while because her only child is grown up, but she told us already that she has no life of her own. She won't be able to go out. She is afraid she will lose her friends. If they need me to, I will stay with the mother for a bit.

I think it is very, very bad that retired people work all their lives to stay independent and then, when they get to retirement or they get sick, the government doesn't allow them to have more than a certain amount of money in the bank. Four, five, six thousand dollars is so little. But when they are denied care, they can't qualify for something like Medicaid, it is ridiculous. I hope you will be able to help these people. I know that we worked all our lives to retire and we worry more and more what we will find ourselves in when we wake up tomorrow.

Without my union I wouldn't be where I am today. The union helped me to live like a decent person, to survive and live a better life. That is what our Friendly Visiting Program does for us when we are retired.

The Retiree Service Department is 22 years old and we have programs for our retirees across the country. Friendly Visiting is our largest service, but we are there for our retirees in many other ways: concerts, classes.

We are always very active in our state and federal government, too, with the guidance of our Legislative Representative, Evelyn Dubrow, and we had better be.

The union doesn't forget us and we would never forget them.

Thank you for inviting me to speak this morning. I want to tell you that as long as I am needed, I will stay with my Retiree Service Department, and if I have the health and strength I will be there to try to make someone else happy.

I would like to thank Judith Wyman, our Associate Director, who is with me today.

Thank you.

Chairman MILLER. Thank you very much.

[Prepared statement of Dorothy Frances follows:]

Prepared Statement of Dorothy Frances, Retiree of the International Ladies Garment Workers Union, New York City

GOOD MORNING: MY NAME IS DOROTHY FRANCES, AND I AM 63 YEARS OLD AND A RETIREE OF THE INTERNATIONAL LADIES' GARMENT WORKERS' UNION FROM NEW YORK CITY; WHERE I AM EMPLOYED BY THE RETIREE SERVICE DEPARTMENT AS A FRIENDLY VISITOR.

AS A FRIENDLY VISITOR WE VISIT RETIRED MEMBERS OF THE ILGWU, INCLUDING THOSE WHO ARE SHUT-IN, AND WHO DEPEND ON SOMEONE TO HELP WITH THEIR DAILY LIVING ACTIVITIES SUCH AS SHOPPING, DOCTORS APPOINTMENTS, PAYING BILLS AND SO ON.

LET ME TELL YOU A LITTLE ABOUT OUR RETIREES - THEY ARE MOSTLY WOMEN, THEIR AVERAGE AGE IS ABOUT 75 YEARS. MOST OF THE RETIREES I SEE ARE IN THEIR 80'S OR 90'S AND THEIR INCOME MOST OF THE TIME ARE VERY LOW; CAN YOU IMAGINE TODAY SOME INCOMES ARE $300.00 OR LESS A MONTH, THEY HAVE TO SKIMP AND DO WITH VERY LITTLE TO HAVE SOMETHING LEFT FOR TOMORROW. IT'S FRIGHTENING FOR THEM TO EVEN THINK OF TODAY, AND WORRY ABOUT WHAT TOMORROW WILL BE.

MOST OF THE RETIREES I VISIT HAVE CHILDREN WHO LIVE OUT OF THE NEW YORK AREA; SOME IN THE SUBURBIA OF NEW YORK. THEY WILL PHONE OR VISIT WHEN THEY CAN FIND THE TIME, BUT A LOT OF THEM DON'T HAVE THE TIME. THEY HAVE THEIR OWN PROBLEMS, THEIR JOBS, THEIR FAMILY AND THE RETIREES DON'T WANT TO WORRY THEIR CHILDREN. THEY FEEL THAT THEY ARE INTRUDING INTO THEIR LIVES.

I HAVE TWO BLIND RETIREES. LAST WEEK I TOOK ONE SHOPPING FOR CLOTHES FOR NEXT WINTER. WE WENT TO DELANCY STREET WHERE WE COULD FIND BARGAINS. SHE IS A VERY PROUD AND INDEPENDENT PERSON AND NOW THAT SHE IS BLIND AND HAS TO DEPEND ON SOMEONE FOR ALMOST EVERYTHING, SHE IS VERY, VERY DEPRESSED, MOST OF THEM ARE. HAVE YOU EVER VISITED RETIREES AND THEY TELL YOU WHEN THEY GO TO BED AT NIGHT THEY PRAY AND ASK GOD TO TAKE THEM IN THEIR SLEEP. I HEAR THIS VERY OFTEN. IT'S

PEOPLE LIKE THESE WHO DEPEND ON US, THE FRIENDLY VISITORS FOR ALMOST EVERYTHING. THEY ARE LONELY DAY AND NIGHT. SOMETIMES AT NIGHT WHEN THEY CAN'T SLEEP, THEY WILL CALL ME AND WE TALK AWHILE. MY HUSBAND CALLS THEM MY CHILDREN.

I THINK AS A FRIENDLY VISITOR WE NOT ONLY HELP OUR RETIREES, WE ALSO HELP THEIR FAMILIES WHO CAN'T BE CLOSE TO THEM. WE HELP THEM TO BE INDEPENDENT OF THEIR CHILDREN.

SOME OF OUR RETIREES TAKE CARE OF THEIR GRANDCHILDREN. IF THEY ARE ABLE, THEY PICK THEM UP AFTER SCHOOL. DAY CARE IS VERY EXPENSIVE AND THEIR GRANDCHILDREN NEED SOME PLACE TO STAY AFTER SCHOOL. THEY FEEL THEY ARE HELPING THEIR CHILDREN, BUT MOST OF THEM ARE NOT CAPABLE.

WE HAVE A SITUATION WHERE TWO GENERATIONS OF OUR RETIREES NEED OUR HELP. A DAUGHTER 62 YEARS OLD IS ABOUT TO RETIRE FROM HER EMPLOYMENT IN THE GARMENT DISTRICT, WHICH SHE ENJOYED, TO TAKE CARE OF HER MOTHER WHO IS 85. THE DOCTOR INFORMED THE DAUGHTER HER MOTHER HAS ALZHEIMERS DISEASE. SHE TOLD US ALREADY, SHE HAS NO LIFE OF HER OWN, SHE WON'T BE ABLE TO GO OUT AND SHE'S AFRAID SHE'LL LOSE HER FRIENDS. THE MOTHER IS IN A SITUATION WHERE SHE HAS TO BE TAKEN CARE OF FOR ALL OF HER NEEDS. AFTER STRUGGLING TO RAISE HER SON, SHE NOW HAS TO FIND TIME FOR HER MOTHER. IF EVER SHE NEEDS A HELPING HAND WITH HER MOTHER, WE, THE FRIENDLY VISITOR WILL ALWAYS FIND TIME FOR HER.

WE TAKE A LOT OF OUR RETIREES TO THE DOCTORS AT THE ILGWU HEALTH CENTER. WE HAVE GOOD DOCTORS FOR JUST ABOUT EVERYTHING. I HOPE ONE DAY WE WILL HAVE OUR OWN DENTAL CLINIC. I AM PROUD TO SEE OUR MEMBERS TAKE ADVANTAGE OF WHAT OUR UNION BUILT FOR US. ONE DAY, I SAW A

RETIREE AT THE HEALTH CENTER. SHE SEEMED TO BE IN HER 80'S. SHE WAS PRETTY FRAIL AND SHE COULDN'T HAVE MADE IT THERE BY HERSELF. I THINK SHE WAS WITH HER GRANDSON. HE WAS VERY ATTENTIVE TO HER, BUT YOU COULD SEE HE WAS A DRUG ADDICT.

WE HAVE RETIREES THAT LIVE IN OLD TENAMENT HOUSES WITH NO ELEVATOR. SOME ON THE 5TH AND 6TH FLOOR. THEY CANNOT GET OUT AND MUST DEPEND ON SOMEONE FOR ALL THEIR NEEDS. THEY OFTEN ASK US WHERE CAN WE GET A DOCTOR FOR A HOUSE CALL? TODAY, OUR RETIREES WHO CAN DO FOR THEMSELVES ARE AFRAID TO BE OUT IN THE STREETS ALONE.

WITHOUT THE UNION, I WOULDN'T BE WHERE I AM TODAY. THE UNION HAS HELPED ME TO LIVE THE LIFE OF A DECENT PERSON - TO SURVIVE AND LIVE A BETTER LIFE. THAT'S WHAT OUR FRIENDLY VISITING PROGRAM DOES FOR US WHEN WE'RE RETIRED.

THE RETIREE SERVICE DEPARTMENT IS 22 YEARS OLD AND WE HAVE PROGRAMS FOR OUR RETIREES ACROSS THE COUNTRY. FRIENDLY VISITING IS OUR LARGEST SERVICE AND WE ARE THERE FOR OUR RETIREES IN MANY OTHER WAYS; CONCERTS, HEALTH CARE CLASSES, OUTINGS AND VACATION INFORMATION.

WE ARE ALWAYS VERY ACTIVE IN OUR STATE AND FEDERAL GOVERNMENT TOO WITH THE GUIDANCE OF OUR LEGISLATIVE REPRESENTATIVE EVELYN DUBROW. WE BETTER BE.

I THINK IT'S VERY, VERY BAD THAT RETIRED PEOPLE WORK ALL THEIR LIVES TO STAY INDEPENDENT AND THEN WHEN THEY GET TO RETIREMENT OR THEY GET SICK, THE GOVERNMENT DOESN'T ALLOW THEM TO HAVE MORE THAN A CERTAIN AMOUNT OF MONEY IN THE BANK. FOUR, FIVE, SIX THOUSAND DOLLARS TODAY IS SO LITTLE; BUT WHEN THEY ARE DENIED CARE, THEY CANNOT QUALIFY FOR MEDICAID - IT'S RIDICULOUS. I HOPE YOU'LL BE ABLE TO HELP THESE PEOPLE. I KNOW THAT WE WORKED ALL OUR LIVES TO RETIRE IN

DIGNITY AND NOT WORRY OURSELVES ABOUT THAT TOMORROW. THE UNION HAS NEVER FORGOTTEN US, AND WE WILL NEVER FORGET THEM.

THANK YOU FOR INVITING ME TO SPEAK TO YOU THIS MORNING. I WANT TO TELL YOU THAT AS LONG AS I'M NEEDED, I WILL STAY WITH MY RETIREE SERVICE DEPARTMENT, AND AS LONG AS I HAVE THE HEALTH AND THE STRENGTH, I WILL BE THERE TO TRY TO MAKE SOMEONE ELSE HAPPY.

I WOULD LIKE TO THANK JUDITH WINEMAN, OUR ASSOCIATE DIRECTOR, WHO IS WITH ME TODAY.

THANK YOU.

Chairman **Miller**. Mr. Nestor.

STATEMENT OF AL NESTOR, DIRECTOR, FRANCONIA FAMILY THERAPY CENTER, ALEXANDRIA, VA

Mr. **Nestor**. Mr. Chairman, I am pleased to be part of these ceremonies today with these great colleagues.

I have been in the mental health profession for 15 years—11 years in the Fairfax County Community Mental Health system as a psychotherapist and Adult Coordinator of Services, and for the last four years as a marriage and family therapist in private practice.

It is my intention in this testimony to present the family systems approach when dealing with problems within the family structure, with special attention given to "women in the middle."

In his book, "Families and Family Therapy," Salvador Minuchin cites a well-known story of a little girl, namely, Alice, who finds herself growing larger as the room that she is in in Wonderland grows smaller. He states that some therapists may concentrate on trying to change Alice, while a family therapist who regards the notion of structural or systems theory would try to assist Alice to change within the context of her room.

This simple illustration helps to point out what therapists have recognized for the last 40 years, that individuals are part of a social system, which usually takes the form of a family, and about half of all visits to psychotherapists, according to the Harvard Medical School Mental Health Letter, arise from problems within the marriage and/or family.

The systems theory approach to families with problems flows from general systems theory. Simply stated, all human life can be arranged hierarchically, which may assume many different configurations. Consistent to this theory would be that all parts of the system are interdependent. The best visual example of this concept would be the mobile; when one part of the mobile is added, taken away or manipulated, it affects the whole.

Family systems create boundaries which have the purpose of maintaining its integrity and homeostasis. These boundaries are reflected in the way that the family system interacts with the environment and is able to adjust to change as a result of internal or external pressure. It is common for the family to enter therapy through the offering of an "identified patient," who then calls attention to the problems within the family as a whole.

Problems occur for families when the system is not able to make the necessary adjustment to change or demands placed on it from either the internal or external environment. An example of this type of situation may be found in the alcoholic family system that maintains a rigid boundary in order to protect the family secret from being discovered. An incredible amount of internal conflict can occur due to their distorted attempts at communication and problem resolution without the benefit of outside intervention.

It is interesting to note that the emphasis on "women in the middle" begins to describe for us a family system with a hierarchal structure. When we think of possible arrangements for this configuration, it may include a spouse as head of household, or an elderly parent may assume this position, rendering both husband and wife the midpoint between this aging parent and their own children.

However, according to the literature, it seems to be women who provide the buffer. R. Bernady, in "An Important New Family Issue," states that, "Of the eight million Americans who provide some level of care to an elderly relative or friend, most are daughters; their average age is 46."

The article further states that one in three of the 1.2 million women who provide care for the severely disabled work outside the home full-time, are more apt to be blue collar workers and less apt to be able to afford outside assistance with housework or child care. Not only are these women providing care for the disabled and elderly, they are more than likely also providing both financial and emotional support for their own children.

So what am I seeing in my practice as a result of this "squeeze"? To begin with, it would be foolish of me to only deal with the woman. I must see her in context to her family system and evaluate from a total system perspective: What is the structural arrangement within the family? Who assumes what role? What is the family's mechanism for handling internal and external demands on the system?

I must attempt to de-focus from "fixing Alice" to focus on the context of her existence, namely, the family.

To begin with, we have to start asking the right questions. Too often, our informational system does not allow for qualitative responses. The typical application for assistance may ask marital status but does not regard the quality of the response. If separated is circled, does this mean legal separation where there is property agreement and financial assistance? Does the form get at the nuances that can occur with other members of the family such as disability which can require added time and expense on the part of the care provider?

If there is a section of the form for qualitative responses, is anyone paying attention to it, and is there a way to know if this is happening?

An example from my caseload would include a mother of four children whose husband is unable to live with the family due to the results of a brain tumor. When she filled out a form in the recent past for federal assistance, she was told by three separate people whose job it was to administer the form to disregard the additional information section because they never pay attention to it.

It is important to know that not only is she providing emotional and financial assistance to her impaired husband, but she also has donated one of her kidneys recently to her daughter, who must remain at home due to her illness, and both of her youngest sons have profound learning disabilities. Is anyone paying attention to the needs of this woman within the context of her total family system?

It is not surprising to me that this woman, in her role of caretaker for husband and impaired children, feels an additional source of stress from the demands of outside agencies.

We must also provide anticipatory support for women in the middle to prepare them for the demands of the outside agencies that they may have to deal with. We must continue to support the many women's centers that are attempting to provide this advocacy through taking into consideration the needs of the total family system and making referrals and recommendations that are appropriate to their unique set of circumstances.

We must also, through our educative process of television and radio, encourage families to communicate with each other regarding the special types of stresses that face families that are dealing with elderly parents, disabled family members, and the reality that the women are providing most of the emotional and financial support.

We need outpatient brief family therapies available for everyone that will also provide medical help. As we have asserted earlier this morning and other testimony has been, certainly I would concur that the schools and churches and civic groups can make tremendous progress and inroads in this. Lay counseling, mother's day out, child care co-ops, the warm lines, the hot lines, for dealing with aging, and dealing with parenting issues, information systems. Organizations like the Cornelia Foundation that we have in Franconia, Virginia, where churches are working together to provide a full range of services. The adult care, day care centers, providing backup for an elderly adult during the day so that the family will get a respite and opportunity to work themselves.

In all, we are talking about keeping the family together and providing hope for them at the point of stress, and seeing stress as an opportunity for creative growth and change. And also, alert to the warning signals that can deeply disturb a family emotionally, and physically.

I hope these brief comments convinced you that we must look at the woman in the context of the family and supporting programming that will address the needs of the individuals within that family system. These values need to be taught on every level. I never met a man or woman for that matter, on her death bed that have said to me, Al, I really should have spent more time at the office. Those are the kinds of values that we need to be teaching at all levels.

Thank you.

[Prepared statement of Al Nestor follows:]

PREPARED STATEMENT OF AL NESTOR, LCSW, DIRECTOR, FRANCONIA FAMILY THERAPY CENTER, ALEXANDRIA, VA

INTRODUCTION:

I would like to thank the committee for the opportunity to testify at this hearing. I have been a mental health professional 15 years - 11 years in the Fairfax County Community Mental Health system as a psychotherapist and Adult Co-ordinator of Services, and for the last four years as a marriage and family therapist in private practice. It is my intention in this testimony to present the family systems approach when dealing with problems within the family structure, with special attention given to "women in the middle".

DISCUSSION:

In his book, Families and Family Therapy, Salvador Minuchin cites a well known story of a little girl, namely Alice, who finds herself growing larger as the room that she is in in Wonderland grows smaller. He states that some therapist may concentrate on trying to "change Alice", while a family therapist who regards the notion of structural or systems theory would try to assist Alice to change within the context of her room. This simple illustration helps to point out what therapist have recognized for the last 40 years - individuals are part of a social system which usually takes the form of a family, and about half of all visits to psychotherapists, according to the Harvard Medical School Mental Health Letter, arise from problems within the marriage and/or family.

Systems theory approach to families with problems flows from general systems theory. Simply stated, all human life can be arranged hierarchiacally which may assume many different configurations. Consistent to this theory would be that all parts of the system are interdependent. The best visual example of this concept would be the mobile - when one part of the mobile is added, taken away or manipulated, it affects the whole.

Family systems create boundaries which have the purpose of maintaining its integrity and homeostasis. These boundaries are reflected in the way that the family system interacts with the environment and is able to adjust to change as a result of internal or external pressure. It is common for the family to enter therapy thru the "offering" of an "identified patient" who then calls attention to the problems within the family as a whole.

Problems occur for families when the system is not able to make the necessary adjustment to change or demands placed on it from either the internal or external environment. An example of this type of situation may be found in the alcoholic family system that maintains a rigid boundary in order to protect the "family secret" from being discovered. An incredible amount of internal conflict can occur due to their distorted attempts at communication and problem resolution without the benefit of outside intervention.

It is interesting to note that the emphasis on "women in the middle" begins to describe for us a family system with a hierarchial structure. When we think of possible arrangements for this configuration it may include a spouse as "head of household", or an elderly parent may assume this position, rendering both husband and wife the mid-point between this aging parent and their own children. However, according to the literature, it seems to be women who provide the buffer. R. Bernady in "An Important New Family Issue" states that "of the eight million Americans who provide some level of care to an elderly relative or friend, most are daughters; their average age is 46". The article further states that one in three of the 1.2 million women who provide care for the severly disabled work outside the home full time, are more apt to be blue collar workers and less apt to be able to afford outside assistance with housework or child care. Not only are these women providing care for the disabled and elderly, they are more than likely also providing both financial and emotional support for their own children.

So, what am I seeing in my practice as a result of this "squeeze"? To begin with, it would be foolish of me to only deal with the woman. I must see her in context to her family system and evaluate from a total system prospective. What is the structural arrangement within the family? Who assumes what role? What is the families mechanism for handling internal and external demands on the system. I must attempt to de-focus from "fixing Alice" to focus on the context of her existence - namely the family.

RECOMMENDATIONS:

To begin with, we have to start asking the right questions. Too often, our informational system does not allow for "qualitative" responses. The typical application for assistance may ask marital status but does not regard the quality of the response. If "separated" is circled, does this mean legal separation where there is property agreement and financial assistance? Does the form get at the nuances that can occur with other members of the family such as disability which can require added time and expense on the part of the care provider? If there is a section of the form for qualitative responses, is any one paying attention to it and is there a way to know if this is happening. An example from my case load would include a mother of four children whose husband is unable to live with the family due to the results of a brain tumor. When she filled out a form in the recent past for federal assistance, she was told by three seperate people whose job it was to administer the form to "disregard" the "Additional Information" section because they "never pay attention to it". It is important to know that not only is she providing emotional and financial assistance to her impaired husband but she also has donated one of her kidneys recently to her daughter who must remain at home due to her illness, and both of her youngest sons have profound learning disabiblities Is anyone paying attention to the needs of this women within the context of her total family system? It is not surprising to me that this women, in her role of caretaker for husband and impaired children feels an additional source of stress from the demands of outside agencies.

We must also provide anticipatory support for women in the middle to prepare them for the demands of the outside agencies that they may have to deal with. We must continue to support the many Womens' Centers who are attempting to provide this advocacy thru taking into consideration the needs of the total family system and making referrals and recommendations that are appropriate to their unique set of circumstances.

We must also thru our educative process of television and radio encourage families to communicate with each other regarding the special types of stresses that face families that are dealing with elderly parents, disabled family members and the reality that the women are providing most of the emotional and financial support. Perhaps this would help to "open up" the fixed boundaries that we have even around social systems such as churches and civic groups to make them aware of the problem and give them specific ways to offer assistance. One excellant example of this would be Meals on Wheels which allows the elderly to remain at home with full assurance that meals will be available. Another example of a program that has given some relief to the "woman in the middle" would be the Adult Day Care Centers which allow the care provider of an elderly adult respite or a chance to continue employment knowing that their loved one would be well cared for.

I hope these brief remarks have convinced you that we must look at women in context to their families and support programming that would address her needs within her family system.

Chairman **Miller**. Thank you very much.

Again, I am somewhat struck by the testimony and of the information that you provided. In these instances, I am always struck by children who are put in difficult situations. Essentially through no fault of their own, something goes wrong and the child finds that they are in an institution or foster home or whatever. Here you find whole families that, because of an event that they essentially have no control over, are thrown into a crisis. This doesn't mean that they won't survive that crisis, but it is in fact a crisis.

And you know, somebody once commented that one of the things that set us apart from maybe more mature societies, or other societies in the world today, was that we were the only country that had three generations of housing. Our parents lived in one house, we lived in another, and our children lived in an apartment while they were at school or what have you. And you know, that was the continuation of "Go West young man." That was the opening of the frontier, generations would be separated and away from one another.

In our family, somebody in Missouri picked up when they were 16, right after they were married, walked across the country in the 1840s to go to California. You get a sense from astronomy, that we are going to Super-Nova and we are about to come back to ourselves. Our children are moving back in after college because they haven't found employment to sustain shelter. Parents are making adjustments to do that. This is really a substantial and dramatic change for the family over where we were during the last 25 or 30 years. I think we were here previously, when America was more on the East Coast, if you will.

Yet, the other thing that strikes me about this crisis, running through the testimony here, is how a little bit of help can be leveraged into a dramatic change in the outcome of that crisis. A couple of hours a week of respite allows somebody to maintain their mental health and not become an abusive individual within the family.

A little bit of counseling might provide the tools for dealing with the dying patient or a child who doesn't understand. Yet finally, through the previous panel's testimony, and yours, is the notion that in many instances, that help is just very difficult to secure, whether it comes from a private agency or volunteers, or especially from the government. Trying to find that particular service to allow this family to survive this crisis in every sense of the word, is difficult.

There is such a terrible mismatching going on here. I remember when we first had a hearing in Anaheim, in Orange County, on parents of severely disabled children and a woman came and testified to us about respite care, and then she told us that she had taken up all of her respite care for two months to give us the testimony. If you ever felt guilty in your life, try that one on as a member of Congress.

She talked about what it meant to be with your child and love your child and to be so intensely engaged with the severely disabled child day and night that there was really no distinction. There was no distinction between day and night or 24 hours, what have you. Then to simply have one or two hours to yourself because somebody can come in and stay in the house for a minute and you can go out and simply do something for yourself. Yet that is not readily available. In California, we finally have some kind of respite care to help these individuals, but it is very sparse.

Let me ask you about the family survival project. You talked about resource care for families of brain damaged adults. Many years ago when you were first starting I spent the morning with a couple of families, and one was a young boy I think who had a motorcycle accident. Do you still provide services to trauma victims like that—victims of automobile and motorcycle accidents?

Ms. KORNBLATT. Yes. We found the people getting lost were those that were not developmentally disabled or with a disability prior to the age of 18 or 21—it varies in the states—and they were not children who were somehow covered at least for education and health care, and not the elderly who were coming under aging services, or mentally ill. This particular group of people with brain impairments were not getting services based on any of the existing systems.

So, yes, we are still, any brain impaired adult.

Chairman MILLER. Trauma cases. OK.

You also talked about the California law that now provides regional resource centers.

Ms. KORNBLATT. Right.

Chairman MILLER. You have merged with that in a sense? I mean, your agency is part of the resources of that center. Have they taken away your responsibility or is this made up of other volunteer agencies that are now the resources?

Ms. KORNBLATT. Family survival project was the one small model project in the late seventies, early eighties. And now, based on that model, the State Department of Mental Health has allocated $3.25 million statewide to replicate that model at seven centers—soon to be eleven centers—throughout the rest of the state.

Family survival project continues to be one of those sites and in addition, we have a new role, we are the statewide resource consultant to help those other centers start out.

Chairman MILLER. You obviously at this point have some state resources. I assume the State is building on the model of private volunteer non-profit, involvement in these issues. Is that correct?

Ms. KORNBLATT. Right.

Chairman MILLER. They are there to facilitate the involvement of the private voluntary centers, is that correct?

Ms. KORNBLATT. Largely it is state funding at the moment.

Chairman MILLER. What will be the outcome? You will have a resource center that will include——

Ms. KORNBLATT. Resource centers in 11 states—information, respite care in the way of on contractual basis, subsidies to families so that they can hire respite workers, or enable their family members to go to day care centers, or spend a night or two on the weekend.

Chairman MILLER. Would you also refer them to an interfaith program, to a church or community based program?

Ms. KORNBLATT. That is where the information part is. I heard somebody ask for hospitals, residential facilities and programs that provide volunteers, counseling, support services. That is under the whole umbrella of information, respite care and support.

Chairman **Miller**. The resource center will become a facilitator?

Ms. **Kornblatt**. Central clearinghouse for all this information and access to services. We do not want to develop new services. We want to develop consortia where existing services just can be accessed or beefed up.

Chairman **Miller**. Ms. Brody, you described a collision of demographic statistics that should cause us great concern, including longevity of parents and single women working outside of the home, fewer children, and the elderly taking care of the elderly. Should we be alarmed? I mean, I guess I am, but some people say I am alarmed at anything.

Ms. **Brody**. Well, I don't know that I would be alarmed about whether people have lots of children or a few. I think that is an option they ought to have. I think the situation is alarming because we as a society have not moved with the times to develop new patterns of services to reflect these broad social changes that we are experiencing.

I am not a bit alarmed about women working. I think as a matter of fact, that apart from the fact that women should have the right to work if they wish——

Chairman **Miller**. What I am asking is, in describing the recipients, the users of this system, to give an expansive notion to the system, you and others have described a rather tenuous, fragile resource. Yet it appears that demographics are working against the maintenance of this existing system.

It doesn't appear that it is going to work in a decade or five or twenty years. The resources, if they don't change something, are going to become even more fragile and more tenuous for people that need them.

Ms. **Brody**. I don't think that we as a society can do it all. We can't prevent all families from experiencing stress. That never will be. I think that we have a responsibility to alleviate some of the conditions that cause them to have stress to the breaking point. That, I think we can do, if we have a solid system of long term care services. I think volunteerism, private agencies, and so on, can do a good deal, but it is the basic heavy services that we must have through social policy.

Volunteers, as I am sure you will confirm, do an enormous amount of good, but they are not the ones who lift and turn bed fast older people who have bed sores. They don't change incontinent older people with Alzheimers disease, who wander out into the cold. That kind of heavy care that some of the older people have nowadays is being done by families and we have gone beyond the point where the families can do it all.

In the same ways—I think Mr. Nestor will agree—in fact therapy and counseling for families who experience emotional stress is very helpful, but that can't do it all either. Since he quoted a family therapist, I will quote one of the earliest family therapists—Dr. Nathan Ackerman, who is now deceased, who wrote a line in his first book I will never forget. That line was: "You can not give therapy to a starving person or to one who is in danger of freezing to death. First, comes attention to those very basic dangerous conditions the person is experiencing." I don't remember the rest of the quote.

This is what I mean, that we must have that long term care system as a basis, so that your centers will have services to which to refer people. There is no point in having a center doing information and referral or counseling if there are no services to refer them to. There is no point in having low medicaid reimbursement for rotten nursing homes. We don't have the right, really, to have oversight and to demand good care, unless we as a society are willing to reimburse for that kind of care.

I think that is the solid, rock bottom that we have to attend to, if we are going to live up to our reputation as a caring society.

Chairman MILLER. Mr. Coats.

Mr. COATS. I was intrigued by Dr. Johnson and by the Robert Wood Johnson Foundation program, and your description of it. I don't know if the Johnson is the same as the Johnson in your name, but I commend that foundation and your involvement in what I think is an interesting and effective program. The concept, I think, is sound.

I have been involved with Big Brothers and Big Sisters for about 20 years or so, and it is very much the same concept. It is going out into the community and enlisting volunteers to provide a limited, but I think effective, amount of help to those who need it. I was impressed with the scope of your activities. In looking at your map, the way you have covered the country with these projects, I was impressed with the response that you received. I can understand if you are offering a $50,000 grant you will get a lot of responses, but what was interesting was the fact that a hundred organizations were turned down, and went ahead anyway and developed the program.

You then suggested that early seed money is needed to hire the executive director and put the program together, and to do some training. Basically, if that was available, you could dramatically, based on the responses you have had, you could dramatically expand this type of service.

Now, you offered a $50,000 grant?

Dr. JOHNSON. Yes.

Mr. COATS. You said something about $20,000 of seed money. What is the differential? Do we need $20,000 or do we need $50,000? What is the potential scope of this type of program?

Dr. JOHNSON. Well, thank you very much for your comments. The interfaith projects and volunteers are a little different, as I said. They are engaged in ministry. They do what they can and often get their hands wet. They are often the family friend of last resort. Sixty percent of the people served live alone, and less than 25 percent are known to any formal agency.

We are talking about the near poor, people who were not eligible for many services. About the money—the budget for 14 congregations working together, with about 300 to 400 volunteers—comes to about $40,000 a year. About $12,000 to $15,000 of that is for a full time director—a poorly paid, highly dedicated person. Seed funds of $20,000 means that a coalition has about 18 months of having a full time director in place; a lead time to get the income from the churches themselves, which comes to about a third of the total budget. And then at a later date to go to the community in general.

What I am saying is that $40,000 a year is the average budget. That $20,000 is enough to move ahead. The first dollar, Mr. Coats, is extremely difficult to get in dealing with churches and synagogues, until the project has proven itself.

Mr. Coats. Are the programs run out of the church itself?

Dr. Johnson. By interfaith coalitions, a union of local, geographically contiguous congregations, whether Jewish or Methodist or Roman Catholic.

Mr. Coats. Do they typically operate out of the church facility?

Dr. Johnson. Yes, and that is an "in kind" service. Basements of some churches are just marvelous.

Mr. Coats. Right.

Now, one thought that occurs to me is that the government, when we get into a legislative program for funding seed money for these kinds of things, or expanding the scope of there are almost daily confrontations with the church-state issue. The State of Washington, as I understand, involved itself in this. How have they avoided problems along those lines?

Dr. Johnson. Well, as I pointed out in my written testimony, I think that this program and its services have many of the aspects of governmental programs in that they are available to all, regardless of race or denomination, income or any other constraining factor. The State of Washington cut out direct payment for chore services and in response to public outcry restored money for volunteer services at a much lower level. For example, a half a million dollars a year for the whole State of Washington.

At this level of funding, the state is able to stimulate throughout the State of Washington volunteer ministries, which are interfaith groups. The money is managed by Catholic Community Services. Funding was first offered to the AAA, who declined. But it really is a very small amount of money—$15,000 to $20,000 per site.

This state-supported program is an example of how you really are enriching the pool of services; you are stimulating volunteer groups to provide such services. As to the church-state issue, there is no evangelicalization, and one is not directly supporting a church service, but you are cooperating with fulfilling the mandate that most people of faith have, that is, to help one another.

Mr. Coats. I suppose those demonstration grants, or that seed money, could obviously be made available to groups outside the Interfaith Coalition?

Dr. Johnson. Yes, for Mrs. Frances' type group—retired union group, or the community organizations Mr. Singleton was talking about. It strikes me—and I guess I have always had a problem with this—that we are overlooking a potentially vast resource of care by not encouraging volunteer projects, whether they are in day care or respite care or elderly care, or other forms of care.

I think a third of the mothers have chosen churches to provide day care services for their children. Often what you find is that there is a volunteer or a worker that is willing to give more because they have extra motives. And while $12,000 sounds a bit low for executive director of such an organization, you are probably able to come up with talented people that are doing it for more than just money.

Mr. COATS. Okay, let me ask you this, Dr. Johnson. What is the potential—now you talk here about 120 million churchgoers, but realistically what is the potential of this? Am I too idealistic in thinking that the church will step in and fill this gap, and therefore government only needs to get involved in terms of the seed money and demonstration grants? What is your estimate of the potential that you are able to do?

Dr. JOHNSON. Well, my estimate is that we have the minimum potential of promoting about 5,000 additional Interfaith Volunteer Caregivers projects in the 50 states.

Mr. COATS. Currently how many are underway?

Dr. JOHNSON. Well, there are many, but of the kind I am talking about there are probably some 500.

Mr. COATS. So you can expand that tenfold, you think.

Dr. JOHNSON. Yes. We know from our other activities—regional conferences throughout the country, where we have met with plenty of people who would want to do this. But it is that first dollar. We know the market is there. And I would say that at a minimum one could have, as part of the movement, some 5,000 Interfaith Volunteer Caregivers projects in the United States.

Mr. COATS. Those 5,000 then would serve roughly how many?

Dr. JOHNSON. Well, it would be about 300 to 400 per project. That would be a conservative estimate.

For instance, the Milwaukee project serves over 8,000 people each year. That is the Milwaukee Interfaith.

But in the rural areas I think about 400 people per year would be about right. There is a variation.

Mr. COATS. Again I commend you. It sounds like a terrific program.

Dr. JOHNSON. I should say, Mr. Coats, that the major impact is strengthening the family. As Dr. Brody said, the family still remains the dominant part of long-term care. But the current environment—of people who are ineligible for public care and what we heard this morning—"Where do I turn? Who will drive me?"—you know very well from your own experience about these little things—that there is really no one who is going to pay for them and there is no place to turn. I think these are the services of volunteers that we are talking about.

When I respond that I don't think volunteer service is an offset, that one does this sort of thing and therefore there is less——

Mr. COATS. But it is a supplement.

Dr. JOHNSON. An important supplement that would be needed under any circumstance. I don't know how one can buy friendship and support from formal agencies, the kind of thing that Interfaith Volunteer Caregivers give to the people they serve.

Mr. COATS. Thank you very much.

Chairman MILLER. Mr. Holloway.

Mr. HOLLOWAY. I don't have a lot to question here, but I guess we are here to endorse a catastrophic insurance bill more than anything else this morning.

Basically I grew up in a home in a very rural area where my mother cared for my grandparents, and my wife grew up in a home in New York City. I think through that I learned what love is all about and got to see it. I think in this world today we are encouraging, you know, who cares for who. I think we have about gotten to that point in this country today.

The Federal Government can't be everything for everyone. I think it is great that we can use our churches. I think that was the intention of this country. I think that was what our Founding Fathers intended, that we use the resources that we have in this country.

My question is—and whoever would like to answer, particularly Ms. Kornblatt or Ms. Brody or Ms. Frances—I assume you all pay income taxes. With the type of bills that we have before us—and I think you saw a quote in the Wall Street Journal that led to the fact that a good child care bill, a good catastrophic bill, a child care bill, would cost between $75 billion and $100 billion, for a good bill, one where we won't have you back here next year testifying before us again.

A good catastrophic bill would probably cost $200 billion, that is 30 percent each we would end up paying.

Are you willing to take another 30 percent out of your salary and put it into long-term health care or child care?

Or let me further that more and ask you, do you think the average American is willing to do that?

Ms. **Brody**. Well, I can only say that the recent Harris survey shows that most Americans are willing to pay for long-term care for older people. That is the best gauge of public opinion.

I think we have to look at the other side of the coin, too, as to what happens if we don't pay for it. What the research has shown most consistently is first that the families have to be given care, that they are stretched beyond their capacity, and that when there are social and health services given by the community, the net result is to strengthen the family and to supplement what the family is doing. It does not substitute for the family. If we don't give the family help, then we are risking family breakdown.

So I think in the sense that we are interested in the family and that we are interested in fostering good family feeling and supporting family feeling, that we don't have any option but to help them go on doing what they have been doing in the past and what they want to do and are still trying to do for the future.

Mr. **Holloway**. I have a child care bill of my own which strictly strengthens the family today. We can't be everything to everyone, I think.

Basically what the average person that I hear testify before me today—not only here but in a lot of the other hearings we have—is saying that we should be everything to everyone.

I agree with you that the average American is willing to pay, but to what point are they willing to pay and at what point are we going to say, as a government, that we have to turn back to ourselves and we have to be willing to do some of it and quit demanding that the government do everything in our country for everyone. I think we are the loser in the return for it.

Ms. **Brody**. That is a question of values. I certainly can't——

Mr. **Holloway**. I am afraid we, as a government, are leading to taking the values away from people.

Ms. **Kornblatt**. I echo what Ms. Brody said and I add that I work full time and I do pay taxes. I also volunteer. I am a volunteer in two different organizations for several hours a week. I also help, financially and otherwise, provide for the care for my stepfather. And, yes, I am willing to help pay for it.

Mr. **Holloway**. 30 percent?

Ms. **Kornblatt**. I don't know where the figures come from——

Mr. **Holloway**. Regardless, are you willing to pay big?

Ms. **Kornblatt**. I am willing to pay, and I don't know exactly what all the figures are, so I am not sure what is big and how big. But, yes.

Mr. **Holloway**. We try to bandaid this together and everybody keeps bandaiding and sticking them on here and there, and I think we have lost touch with where we are trying to go as a government.

Ms. **Frances**. I think, as a retiree, we have already paid our dues. We paid taxes and we paid into our retirement. I don't understand why, after working all our lives and paying the government our taxes, we come to a point today where we see people living out in the streets—and I am speaking about retired elderly people in their 70s and 80s. We paid so that we would be able to get back—at least that is what we were told, that we were paying into something to get something back.

Regardless of the percentage, what the government asked is what we paid. I don't think it is right that after working, you would call it a lifetime—it is only now that we are living to be much older. My grandmother lived to 103 and my husband and I took care of her for 22 years, 23 years, before she passed. I was a nervous wreck when she passed, and I was told that I would end up maybe in the graveyard before she would.

Mr. **Holloway**. Now you are a better person for it because you are out helping other people now.

Ms. **Frances**. Yes, I am. I hope somebody will be out there to help me, because if this continues the way they are going and I can't pay my rent—I see people out in the street—that I might be out there just like them. So that is not what I paid my retirement for.

Mr. **Holloway**. We have set up Medicaid, Medicare, all types of things in this government, and I hear more people complaining about what we have done, that we are not doing enough.

Ms. **Frances**. But you also have a law that if we retirees have more than $5,000 in the bank—today $5,000 is nothing. Like I said, even $6,000 is nothing. That won't even carry you six months. If you are living in a decent place, you pay $700 or $800 a month. So——

Mr. **Holloway**. I agree. We encourage people to lie to get on it.

Ms. **Frances**. I don't want to lie, and I want to live decently.

Mr. **Holloway**. The people I see deserving that account get it which are just above the level to where we set them. I think we just have to back up and I hope the Members of Congress will all back up and look at where we go.

Ms. **Frances**. I hope they will put us on the same pedestal they are on and realize we need more money to live off of.

Mr. **Holloway**. I wish they would also.

Mr. **Nestor**. Can I speak to that?

Also I work full-time and pay my taxes and I also would be willing to support the long-term health insurance bills. I think my concern is that so many of our values have changed, as you implied, in the last decade or two, and we have that "Me" generation of the 1970s which is very much into changing the channel when it hurts and when it is not pleasing me, and we get into serial monogamy very fast.

The case I illustrated typifies when we start to hurt in the family, often before we ask for the services, we think about breaking up a marriage and changing partners, thinking somehow the grass is greener on the other side, but not realizing there still has to be a method. That "Me" generation I think has really hurt us.

Now, the brief counseling/psychotherapy programs that I would recommend would be really committed to the needs of people, where they would be paying for services and, as much as possible, really trying to encourage return to some values that we have lost.

Mr. HOLLOWAY. Thank you.

I have no further questions.

Chairman MILLER. Mr. Weiss.

Mr. WEISS. Thank you very much, Mr. Chairman.

There is always a great temptation on this side of the table to take over the role of the witnesses and to testify. I guess I am just as guilty of that as anybody else.

Just in the context of the last discussion that took place, I know that my reading has indicated to me that it is not necessary that we have to spend more money on adequate health care in this country, but it is a matter of how that money is spent.

We spend, as a nation, a larger percentage of our Gross National Product than many other countries. We don't get the value for our money.

My constituents would not be satisfied if I sat through this discussion and did not suggest that there be a national health care program which in fact provides care for everybody who needs it, rather than having 37 million Americans, as we have right now, without any health care protection, any health insurance of any kind, governmental or private.

As far as Medicare—which there is a suggestion that government has done all of this—today senior citizens are paying more of their personal income for health care than they did before Medicare was adopted. So it is not that we made any real advances in dollars and cents terms.

We have some systems in place, but it is fragmented, and we ought to be thinking about what services we actually deliver to people, rather than on the systems that we have got in place. That is my testifying.

Ms. Frances, let me welcome you personally. You come from my area.

I will ask you to expand, if you would, a little bit about the kind of people whom you visit.

There is a suggestion, for example, that children of these people whom you visit ought to be doing more by way of taking care of their parents.

Where are the children of the people whom you visit, by and large?

Ms. **Frances**. Most of the children of the people I visit are not in the city with their parents. They live as far away as California and other places at a great distance. They have their families, they have their jobs, and they just don't find the time that they want to find. I am not saying they can't find the time, but not the time that they want to find with their parents.

Then on the other hand, the parents hide whatever they can from their children, so if the children really don't visit the parents, they don't know the situation the parents are in.

Yesterday I had to go to two sisters who live together. They hadn't paid their rent for two months and they got a letter from the office, and right away they called me. I said, well, the best thing to do is go directly to the office and see what is really wrong, because I know that both of them are not capable of remembering if they paid this bill or that bill.

Some of them can't even take the medicine that is given to them to take because they have so many different medicines to take for so many different things, and they get their medicines mixed up.

So we need to have a system wherein after you reach a certain age and it is found out that you know these people are not able to take care of themselves, we need to have something set up that these people are not on their own.

You really don't know the situation they are in until you actually go and see them. They are dirty sometimes. They are not eating well. They just become children again. They need somebody to oversee them. A lot of them live alone. It is just heartbreaking to see them.

Mr. **Weiss**. What we need, I assume you are saying, is not necessarily institutionalization, but somebody to come on a more regular basis in their own homes.

Ms. **Frances**. Right. I think they are better off in their homes than they are in an institution, if they can just have someone to come in and see about them, to be a mother to them. This is what they need.

The nursing homes, unless you have the money to really pay, you don't get into a decent nursing home, and you call us the middle class. We would never be able to live in a decent nursing home because we don't have the money to pay.

What the government called money for poor people—I mean, like I said before, it is just ridiculous.

Mr. **Weiss**. Thank you very much.

I am sorry I was late. I had another subcommittee in a different area.

I want to say, Mr. Chairman, that people in organizations such as those represented by the witnesses really do need additional support because, as it is, they are barely able to touch the problem, and they need additional backup support so that in fact the people who serve can be served with a little more dignity.

Thank you very much.

Chairman **Miller**. Thank you.

I am shocked at what I just heard by my colleague, Mr. Holloway. Unfortunately he wasn't here for the first panel.

Mr. Nestor, I have to tell you that I am amazed at your comment, when the entire previous panel was made up of children of the 1970s, the "Me" generation, all of whom are working so hard to keep their families together. If you look at Ms. Brody's testimony, you will find this is made up of granddaughters who are 30 to 40 to 50 years old, all of whom experienced some of the 1970s. Yet they are doing everything we say we want a family to do and they can't hold it together, except by becoming poorer, by becoming more stressed, by having a divorce, not because it was easy but because somebody couldn't take it anymore. Somehow our response is they don't need help.

I think also I am amazed at the failure to delineate the services that are required. Child care is going to have to be done in a mosaic. Churches and corporations and everybody will have to work together.

There is a level of services for which there is no private sector. Mrs. Brady's son has cerebral palsy. Constant suction is required of his tracheostomy. Those services don't come in volunteerism in any significant numbers to deal with the problems.

The families who were before us last year had the children in the room and maybe that is what the Members of Congress need to see. We had children who simply were all going to die. Their families wanted one thing: they wanted the children at home, they wanted to take care of their own, but government policies wouldn't allow it and their insurance policies wouldn't allow it. They can all have their children in institutions, in hospitals, but for a third or a quarter or a tenth of the cost they couldn't have their children at home unless they gave up their jobs, their homes, their cars, another child's college education.

That is just not what America is about. That doesn't strengthen the family.

I am watching my own family, with my aunt, who has Alzheimer's disease, go through this. Her son is a pilot on the Panama Canal. Her other son is a sea captain, based out of Florida. You don't think they worry? Her son comes home almost once a week from Florida. He has a new family, new children. He is trying to balance those two. He is not reaching into the government's pocket; he is reaching into his own pocket. My mother is taking care of her sister almost full-time.

Do you know what we can't find? A few little services to figure out how to help this woman a small part of the day.

I am amazed that somehow the testimony of that previous panel would be turned into a notion that these people were sitting back in an easy chair saying, "Take care of my family."

Ms. Brady talked about taking care of her son Mathew 24 hours a day. That is what it is. You know, you would need three volunteers because the volunteers would have their own families. There is no such thing as around-the-clock volunteers. That is not to put down volunteerism, because without that the other part will not work, the respite, Meals on Wheels and all of the things we think will sustain people in a more lively and coherent fashion within their own communities.

You know, don't get me going here. I guess maybe that is why I think this debate over long-term care is going to be so incredible. If the baby boomers thought about the issues and were rushing at them, even if they were yuppies, if I am hearing in my community what I am hearing in my own family and what other Members of Congress are hearing, the baby boomers haven't encountered anything.

I was married when I was 18. My children are in college. A lot of people haven't experienced that delight yet as their parents grow older, but they are going to.

I had not heard this term before this morning, in reading the briefing papers: the "sandwich" generation. It hurts, that people would consider themselves in that situation, especially where you have California cuisine, you are not terribly complimentary to sandwiches.

We won't get into that.

Thank you very much.

[Whereupon, at 12:25 p.m., the hearing was adjourned.]

[Material submitted for inclusion in the record follows:]

EXCERPT FROM: Arthur C. Emlen, Paul E. Koren, and Dianne Louise, Child and Elder Care: Final Report of an Employee Survey at the Sisters of Providence. Portland, Oregon: Regional Research Institute for Human Services, Portland State University, 1988.

The "Sandwich Generation": Employees who have children and are also helping out or caring for disabled or older adults.

Of the 20-site Sisters of Providence workforce, 47% have children under the age of 18 living at home and 22% bear some responsibility for a disabled adult or adult age 60 or older. Seven percent have both, and 62% have either one or the other kind of dependent care resposnsibility. The 7 percent represent 15% of the parents and 34% of those with adult dependent care.

What do the data say about the 7% -- the so-called "sandwich generation" who report some form of responsibility for adult care at the same time that they still have children at home to raise and for whom to arrange child care? How much extra difficulty is posed by their double-care responsibilities? Since 85% of these employees are women (80% of Providence parents are women and 85% of Providence employees with adult care are women), it will simplify the analysis just to look at the women employees (n=400 which is 8% of the Providence sample of women employees).

These sandwiched mothers are on the average two years older than employed mothers in general and four years younger than all women employees who report some adult care responsibility. So they are also somewhat less likely to have young children of child care age -- 38% of them having a child under age 6 compared to 49% of all employed mothers. However, they are less typical of all employees with adult care, of whom only 14% have a child under 6 years of age.

The child care picture for the sandwiched women employees is that 93% reported arranging some form of child care for their children under age 18, 40% purchased child care, 37% claimed a child care tax credit, 32% purchased out-of-home care, such as family day care or center care, and 9% purchased in-home child care. Compared to all employed mothers, they were somewhat less likely to use child care outside their homes, and perhaps for this reason they also were somewhat less likely to experience instability in their child care as measured by past changes or plans to change arrangements.

The adult care picture is different, because 80% of those persons whom employees were looking after reside elsewhere than in the employee's home, 16% more than 100 miles away. Most of these persons are economically independent and largely taking care of themselves. Twelve percent of the sandwiched mothers had a disabled adult (between 18 and 60) in the household and 14% had an adult 60 years or older at home. Only 5% of the 400 employed mothers with adult care claimed a tax credit for adult dependent care.

How did these double-care employees fare in their efforts to combine working with family responsibilities? In general, compared to all women employees who had responsibility for child care or for all those attending to disabled adult or elder care , it is evident that they did tend to report somewhat more difficulty, worry, stress, and time loss from work, although the differences are small. For example, 73% of mothers with dual care responsibilities reported difficulty finding adult care, compared to 66% of all employees with adult care, and 55% reported difficulty paying for child care, compared to 48% of all employed mothers. Those with both children and adult care also were more likely to report worry and stress from their family finances-- 70%, compared to 64% of all mothers and 59% aof all with adult care.

The differences would be greater, if our attention were more narrowly focused on those who carry a heavy burden of personal care for disabled adults or frail elderly while at the same time trying to manage child care and working. And the differences would be greater if we compared "pure" categories: child care *only*, double care, and disabled or elder care *only*.

In our 1987 Portland survey of 33 companies and agencies, the difficulty for women employees, by type of dependent care, ranged from 16% of employees having *no* dependent care responsibility to 47% of those who had children under 18 *and* were caring for disabled adults. It was 41% of those with children *only* and 46% of those with children plus elder care. Among Providence employees, the figures were 43%, 46%, and 33% respectively of employees with children (but not child care only), double care, and adult care (but not adult care only).

The obvious conclusion is that employees' perceived difficulty combining work and family does indeed depend upon how much dependent care responsibility they bear. These "sandwiched" employees report the same kinds of problems as other employees, only somewhat more so. Our attention, therefore, is directed to the specific issues that have emerged as critical for all employees with dependent care, such as how to find it, how to manage it, and how to negotiate some workplace flexibility or accommodation that will enable employees to balance better the demands of working with family responsibilities.

PREPARED STATEMENT OF BARBARA KANE, LICENSED CLINICAL SOCIAL WORKER AND CO-DIRECTOR OF AGING NETWORK SERVICES, INC., BETHESDA, MD

America has awakened to her status as an aging society. All our major media have recently chronicled this phenomena, including Newsweek, The Washington Post and the Today Show. Some of our nation's greatest minds are pondering our preparedness to cope with, and care for, our "greying population", but as national agendas shift and as new policies are debated we encourage you to focus briefly on one particular slice of the current scene, namely the family caregiver who provides care on a long distance basis.

America is a mobile society, stretched across an entire continent. Where once children grew up and took their place among their parents in home towns, our mobile lifestyle has fragmented the traditional family in ways we could never anticipate. The result is most graphically depicted in the ads for long-distance telephone service: middle aged children "reaching out to touch" an elder parent time zones away.

Unfortunately long-distance phone conversations no matter how touching, are but one of the many aspects of caregiving. I want to talk about what else is involved.

My colleague, Grace Lebow and I are both licensed clinical social workers, specializing in geriatrics. We frequently consult with adult children about their elderly relatives living far away. These family members often come to us with significant stress related health symptoms such as depression, backaches, GI problems and many have resorted to alcohol as a way of dealing with the need for relief.

As we worked with more and more people suffering from incredible amounts of responsibility and stress, we realized the need for a more organized way to assist such persons. In response we started Aging Network Services in 1982. Aging Network Services is a nationwide network of hand picked and carefully screened social work professionals who provide local assistance to parents and relatives across the country. Our network is comprised of master degree social workers who are licensed and meet the professional independent practice standards of their state. They must have a private practice, a significant amount of geriatric experience, and coverage at all times. Our clients can be typified, perhaps by the following story of a woman whom I will call Phyllis.

Phyllis lives here in the District of Columbia, and her 75 year old mother lives alone in Tampa, FL. Phyllis works full time for the federal goverment. She is married with two school-aged children at home, ages 7 and 9. Both are good students, and quite active in after school activities. Organizing car pools, helping with homework and seeing to their daily needs leaves Phyllis little time for relaxation during the week. On top of this, she feels constant responsibility to her mother and finds herself flying to Florida more and more often. This means lost income, and possibly some jeopardy to her job as well.

"It's over a year since mother broke her hip, yet she sounds more and more unhappy," Phyllis complained initially. " She lives alone in her own home and insists on remaining there even though she is lonely and has no family nearby. She is becoming so forgetful that I am fearful for her safety, especially after the night she left the gas burner on. Now that she can't drive anymore, it is truly difficult for her to take care of herself. She refuses to make any changes and only wants me to be with her and listen to her daily misery. I am developing migraines for the first time in my life. Last month, I made 3 trips to Florida to see mother because she sounded so depressed. It's no coincidence that my seven year old started to overeat. I know she is troubled by my absence."

Phyllis' mother has her on thoughts on living far from her daughter, "How can I be happy when I have no one to turn to nearby. But I manage somehow and I don't feel ready to move to Washington, as Phyllis wants. It's not so easy to make a move at my age. I'm used to it here, and if I return to Washington I'll still be alone when Phyllis travels. I don't know what to do. Maybe time will bring answers."

Phyllis came to us in desparation. She had seen and kept a news clipping about our service for 2 years before finally calling. She, like many people are reluctant to use professionals especially for very personal and private matters.

But what prompted Phyllis to call was that she felt pulled in all directions. In a caregiver support group at her place of employment, she realized that she was a double duty caregiver and that it was taking its toll on her whole family and her job.

The stress had piled up. Phyllis started to fight with her husband. He felt she should be more assertive with mother about hiring help so she wouldn't have to run down so often. She was also distracted at work by the numerous calls from mother. The situation was beoming increasingly unmanageable and untenable.

Phyllis did get help from us. We selected a Network social worker from Tampa, who began visiting her mother on a weekly basis. They began to work towards how mother could more comfortably stay at home. Over a 2 month period, mother accepted a home health aide to prepare meals for her 4 hours every day and a physical therapist to strengthen the use of her hip and improve ambulation.

Our social worker selected these services based on the clients' limited budget and the social workers' experience with the providers. Mother's mood began to improve after about 3 months. She re-engaged with her friends and prior social organizations. Phone calls between Phyllis and her mother are less tense.

It is one year later now. Our social worker is available to mother and visits periodically. Phyllis travels to Florida monthly, but the trips are planned now, and they are less draining.

I am not a researcher so I cannot quote statistics about how many Phyllis' are out there. But I am a clinician and I have seen hundreds of families over the course of the past seven years, who have legitimate and serious concerns about themselves, their older family members, and how to survive the onslaught of external demands and internal guilt about not doing enough.

With almost no exception, my older adult clients want to remain in their homes. But there is not a lot of help available for community caregiving. When it is available, it is often not what our clients would prefer, nor is it really appropriate, such as a nursing home for Phyllis' mother.

Very possibly, had Aging Network Services not been there, Phyllis would have tried to place her mother in a nursing home. It was an option Phyllis considered and rejected early on. But it has happened in many cases where the problems were no more severe. I think we have to be careful about supporting the development of long term care insurance that does not provide substantial options for community care programs.

While resources for community programs are increasingly needed, resources for the caregiver are also important. From our viewpoint, keeping the caregiver involved is what it is all about. This means providing services directly to caregivers. Some of these services like respite care will not be cheap, but consider the alternative.

Some of what is desperately needed, however, is not expensive. Raising the awareness of employers about their employees elder caregiving responsibilities would help. I am told these responsibilities are borne by 1 in 4 employees over age 45.

In the face of this need, our network has developed a national eldercare information and referral service for employees who are concerned for their older family members. Greater productivity, loyality and reduced absenteeism all accrue as benefits from employees eldercare programs.

In addition to information and referral, other low cost employer activities include allowing medical leave for caregiving tasks, organizing lunch time and after hour support groups, and training employee assistance program counsellors about eldercare issues.

Based on my clinical experience here in the Washington area, I also believe the Federal Goverment as a large employer, should consider offering these kind of benefits because I know how much suffering some people have endured.

Supporting the older person means improving the services and opportunities available to caregivers, who by the way, are getting older themselves. The caregiving they offer daily whether parents are nearby or at a distance are of immeasurable value. We need to sustain and assure these contributions in the best way we can.

Thank you.

PREPARED STATEMENT OF A. JANE ROBERTS, PH.D., MEMBER, AARP STATE LEGISLATIVE COMMITTEE FOR IOWA, DES MOINES, IA

An affordable public policy requires that families continue to provide most of the long-term care for impaired elders. These unpaid family members, mostly women, save the government a substantial amount of money in Medicaid payments to nursing homes. Because of the increased longevity of elders and the fact that women are delaying childbirth until their later years, many caregivers are playing a dual role as caregiver for their own children and their aging parents. The demands and pressures on their lives are tremendous. Family caregiving is an act of love and committment but it also involves great sacrifices, physically, emotionally and financially.

A responsible, humane public policy requires that government recognize the family caregiving contributions through expansion of the dependent care tax credit program to include workers with elder care responsibilities; legislation to provide unpaid leave and job protection to workers caring for a seriously ill parent; and provision for actual services and periodic relief from their caregiving burden.

A. Jane Roberts, Ph.D.
Member, AARP State Legislative Committee for Iowa
1223 46th Street, Des Moines, Iowa 50311
Phone: 515 279 8352

Statement of
the American Association of Retired Persons
on "Double Duty: Caring for Children & the Elderly"

There are many catastrophes which can strike a family. It may be the loss of a job, a divorce, or the sudden death of a loved one. But few lead to the emotional and financial devastation which so often accompanies a long-term disabling illness. And there are few for which society offers so little help.

The vast majority of long-term care in our country is provided by family members, often at considerable emotional and financial sacrifice. Who are the caregivers? Those caring for frail older persons are predominantly adult children and spouses. The great majority are women. These caregivers -- who are the real "case managers" -- are a highly vulnerable group. Many of the spouses are themselves elderly, poor, and in ill health. Many of the adult daughters caring for older parents, typically middle-aged women, are working outside of the home -- caught between trying to help with a child's college education and trying to give a frail parent the help she needs. Others, the focus of this hearing, are simultaneously providing care to frail parents and to their own young children. Yet another group of caregivers subject to multiple stresses in the home and in the labor force are the parents of chronically ill children. Many of these caregivers, along with persons caring for Alzheimer's victims, have had to adjust to what has been termed "the 36 hour day."

More than a decade of research has documented that caring for the dependent elderly is difficult emotionally, physically, and financially. The emotional stresses range from feeling trapped and isolated to being clinically depressed. The sheer physical burden of caregiving, which often involves strenuous lifting and housework, can affect the carer's own health status. Over time, such strains often lead to disruptions in the entire family system. The financial cost of caregiving includes not only the direct costs of care, but the income foregone through working fewer hours or giving up one's job, not being able to advance one's career, and losing Social Security credits.

AARP is vitally interested in family caregiving issues. Our members are not only the recipients of family care, but large numbers are caregivers themselves. According to the 1982 National Long Term Care Survey, the average age of women providing care to disabled older spouses is 69, and the average age of women providing care to disabled older parents is 52. It is probable that large numbers of AARP members, both male and female, are caring for frail relatives. And millions more have had direct experience with the need for long term care in their families, a fact which is true for a surprisingly large percentage of Americans of all ages. According to a poll conducted for AARP and the Villers Foundation by R L Associates, 61% of persons aged 18 and older have dealt with the need for long term care either in their own families or through a close personal friend, and an additional 20% expect to face the problem within the next five years.

Because the issue of caregiving is so important to our membership, AARP and The Travelers Foundation recently contracted with Opinion Research Corporation, to conduct a national survey of caregivers. Of particular salience to this hearing are preliminary data indicating that 34% percent of primary caregivers for the elderly have children in their household. Twenty-six percent of primary caregivers have children under the age of 12, and 21% have children between the ages of 12 and 17. These data buttress those from the 1982 National Long Term Care Survey indicating that 25% of adult daughters caring for frail parents have simultaneous responsibility for children. Together, these two surveys suggest that the experience of families caring for children and chronically ill parents at the same time is far from an isolated phenomenon. It is also likely to be one which is even more common in the future due to the trend toward childbearing at later ages. Aging "baby boomers" may be increasingly squeezed between the need to devote time to their children, to their jobs, and to parents who need home care and related services.

Other social and demographic trends, such as the influx of women into the labor force and the dramatic growth in the numbers of persons aged 85 and over, are intensifying the demands upon caregivers. The most rapidly growing segment of the female labor force is middle-aged women, who are also the group most likely to be caring for frail parents. Indeed, more than 62% of women aged 45-54 work outside of the home, a higher percentage than for women of all ages. More than half of AARP's seven million working members are women.

AARP's many working members with significant family care responsibilities suffer substantial economic costs if they must give up their jobs in order to provide care. In the short run, the lack of a job protection for workers who must care for a family member is a financial hardship for the many families who rely upon two incomes. But the long-term economic effects are even more devastating. Frequent breaks in employment to provide family care make it difficult for a woman of any age to earn - or vest in - adequate pension benefits and Social Security income. This problem is compounded by the fact that midlife women can face both sex and age discrimination when looking for a new job. Minority women are often subject to racial discrimination as well.

Time out of the workforce to care for family members is one factor in the gloomy retirement income picture for many of today's older women. Only 21% of women over age 65 receive private or public pension benefits, compared to 45% of men. Of the very small percentage (roughly 12%) receiving private pensions, the average monthly check for an older woman is half that of an older man. Average total retirement income for a single women over 65 is only two-thirds that of a single man over 65, and is only marginally above the poverty level.

Business has good reasons for helping their employees deal with elder care and family care responsibilities. An AARP "Caregivers in the Workplace" survey found that 40% of working caregivers were employed with the same company for 10 years - a loyal, well-trained and hard-to-replace workforce. A study by The Travelers Foundation found that almost a third of the employees surveyed spend an average of more than 10 hours a week caring for a relative or friend older than age 55. If caregivers must carry on alone, they may not be as effective workers as they could be if employers provided some help. Recent surveys in other worksites reveal similar figures.

Eldercare programs and services provide much needed support to workers while fostering good public relations among employees and in the community. Along with Travelers, companies such as Aerospace, Florida Power & Light, Hewitt Associates, Pepsico, and Wang Laboratories have begun to develop ways to help employees cope. These include providing information and referral, ongoing training, and offering flexible hours and scheduling.

Some employers offer employer-assisted plans for dependent care. While a step in the right direction, these plans are very limited by IRS regulations. Other employers provide information about the Dependent Care Tax Credit. (Many employees know that this credit covers employment related childcare expenses, but are not aware that it may also be used for the care of adult dependents, such as parents, spouses, or adult children.)

AARP is one of many concerned groups working on the issue of caregiving from a variety of perspectives. We have published resource books and educational materials for caregivers; we work with community organizations and employers to develop workshops and related caregivers programs, and we have developed training programs and information on home nursing skills.

On the legislative front, AARP strongly supports legislation to expand supportive services for caregivers to the frail elderly and to protect their jobs. Both respite care and adult day health care, for example, should be covered under Medicare, and AARP has worked actively in support of a modest respite care benefit as part of the Catastrophic Medical Protection Act of 1987. Penalties for family care (such as the reduction of benefits under the Supplemental Security Income program when the beneficiary lives with his/her family) should be eliminated. And we hope that the Family & Medical Leave Act now being considered by the House of Representatives and Senate will be expanded to protect the jobs of those who care for any family member, including spouses or other relatives living with the worker, in addition to parents or children.

AARP commends this committee for drawing attention to the strains on family caregivers, especially those caring simultaneously for elderly parents and their own children. The situation of this group in particular places in sharp relief the need for our nation to develop family-centered social policies which support families across the entire life course.

○